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**Experiences of specialist inpatient treatment for anorexia  
nervosa: A qualitative study from adult patients' perspectives**

**Vivien Smith**

**Doctorate in Clinical Psychology**

**The University of Edinburgh**

**February 2011**

## DECLARATION

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## DEDICATION

“There is no magic cure, no making it all go away forever. There are only small steps upward; an easier day, an unexpected laugh, a mirror that doesn't matter anymore.”  
(from Anderson, 2009, p.278)

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For Ava and Gavin

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## ABSTRACT

**Background:** Response to treatment in anorexia nervosa entails various challenges, including an increased risk of relapse and re-admission in those treated as inpatients. A better understanding of patients' experiences is paramount to improve treatment acceptability and outcome. This qualitative study aimed to explore the lived experiences of adult female inpatients undergoing a specialist inpatient treatment programme for anorexia nervosa.

**Methods:** Semi-structured interviews were carried out with 21 female participants (aged 18-41 years) with a diagnosis of anorexia nervosa, undergoing treatment in a specialist inpatient eating disorder unit. Data were analysed using interpretative phenomenological analysis (IPA).

**Results:** Qualitative analysis highlighted 5 master themes which underpinned treatment experiences: (1) Shifts in control, (2) Experience of transition, (3) The importance of supportive staff relationships, (4) Sharing with peers and (5) Process of recovery and self-discovery.

**Conclusions:** Overall, findings suggest patients experience a process of change and adjustment during inpatient treatment in relation to their levels of perceived control, attachment to the treatment environment and a sense of self-identity. Treatment experiences appear to be influenced by the development of supportive relationships and the provision of individualised care.

**Title**

**Treatment perceptions of patients with anorexia nervosa:**

**A systematic review of qualitative studies**

**Abbreviated Title for Running Head**

Review of treatment perceptions in anorexia nervosa

## **ABSTRACT**

**Objective:** The purpose of this paper was to conduct a systematic review of the current literature that explores patients' perceptions of treatment for anorexia nervosa (AN).

**Methods:** Studies were obtained from systematic searches of literature published between January 1990 and August 2010 using PubMed, CINAHL and PsycINFO. Studies were selected if they explored treatment perceptions in anorexia nervosa and used a qualitative design. The methodological quality of the studies was critically appraised by multiple reviewers.

**Results:** Fourteen qualitative studies met the criteria of the present review. Findings suggest that patients value the therapeutic relationship and interventions which address their psychological needs. Existing concerns relate to an overemphasis on weight restoration, service inaccessibility and professional practice. Current findings are limited by methodological weaknesses in the literature.

**Conclusions:** Considering patients' perceptions of treatment may improve effectiveness and satisfaction. Findings highlight a need to reconsider clinical practice, training and service design.

**Keywords:** anorexia nervosa, treatment, perceptions, review, qualitative research

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## INTRODUCTION

Anorexia nervosa (AN) is associated with high mortality rates and co-morbid psychopathology and medical complications (Agras *et al.*, 2004; Granek, 2007). Response to treatment is problematic as less than half of individuals fully recover and approximately 20% experience chronic symptoms (Seinhausen, 2002). Those in recovery tend to present with poor weight maintenance after treatment, while there is an increased risk for relapse and readmission amongst those treated as inpatients (Vandereycken, 2003). Drop out rates are high in this population, suggesting dissatisfaction with treatment and/or services (Mahon, 2000). Treatment for AN presents financial implications to healthcare services due to the need for repeated episodes of hospitalisation and long-term health care. The literature on treatment effectiveness in anorexia nervosa is limited and it remains unclear how treatment contributes to patient recovery and overall wellbeing (Agras *et al.*, 2004).

Within the United Kingdom, there is increasing recognition of the importance of patients' involvement in the development of effective treatments and services in healthcare settings (Newton, 2001). The involvement of patients' experiences may help to modify services to meet patients' expectations and increase treatment acceptability (DOH, 1999, 2004). Specifically, The National Institute of Clinical Excellence (NICE, 2004), highlights the importance of patient and carer satisfaction in the assessment of treatment effectiveness for eating disorders. However, assessment of treatment quality is multifaceted and should include information based on the structure, process and outcomes of treatment and services (Donabedian, 1980). Perceptions of treatment in eating disorders should make reference to the availability, acceptability, effectiveness and accessibility of care (Newton, 2001).

Until recently, there has been a dearth of eating disorder research from the patient's perspective, with studies of treatment quality and effectiveness focussing on clinical outcomes using quantitative methodologies (Bell, 2003; Newton, Robinson & Hartley, 1993). Existing research exploring patient perspectives of eating disorders has focussed mainly on experiences of having an eating disorder and the identification of recovery factors, with perceptions of treatment and services remaining largely neglected (Vanderlinden, Buis, Pieters & Probst, 2007). There remains a growing need to explore perceptions of treatment quality, particularly for AN, to address difficulties with treatment adherence and outcome (De la Rie, Noordenbos, Donker & Furth, 2008).

Previous qualitative research has explored patient satisfaction and experiences of treatment, mainly in mixed eating disorder samples (Bell, 2003; Espindola & Blay, 2009). Studies of patient satisfaction of eating disorders treatment remain inconclusive. In Petterson and Rosenvinge (2002) over half of patients attributed their recovery from their eating disorder to the treatment that they received. In a large patient satisfaction study, Clinton, Bjorck, Sohlberg and Norring (2004) found that while two thirds of patients were satisfied with their eating disorder treatment, approximately a third of patients felt unsatisfied 3 years post-treatment.

Research suggests that the delivery of eating disorders treatment is just as important to patients' as the content of treatment programmes (Bell, 2003). ). In their recent meta-synthesis of patients' perceptions of the recovery process for AN, Espindola and Blay (2009) highlighted the therapeutic alliance as an important facilitating factor for change. Non-specific therapeutic factors, such as good communication, understanding and pacing the timing of treatment are seen as crucial by patients (De la Rie, Noorenbos, Donker & Van Furth, 2006; De la Rie *et al.*, 2008; Le Grange & Gelman, 1998; Petterson & Rosenvinge, 2002; Reid, Burr, Williams, Hammersley,



2008; Swain-Campbell, Surgenor & Snell, 2001; Vanderlinden *et al.*, 2007). For patients, interventions which address both underlying psychological issues and physical outcomes are viewed as essential for recovery (Bell, 2003; Le Grange & Gelman, 1998, Newton *et al.*, 2003; Vanderlinden *et al.*, 2007). Patients identified the importance of the availability of specialist services with experienced staff (De la Rie *et al.*, 2006, 2008; Escobar-Koch *et al.*, 2010; Reid *et al.*, 2008; Swain-Campbell *et al.*, 2001). The current literature highlights patients' concerns regarding poor availability of services due to gaps in services, extended waiting lists and the lack of specialist eating disorder knowledge in health professionals, specifically general practitioners (Escobar-Koch *et al.*, 2010; Newton *et al.*, 2003; Reid *et al.*, 2008; Swain-Campbell *et al.*, 2001). In addition, patients have identified issues relating to inadequate service transitions and follow-up care (Escobar-Koch *et al.*, 2010).

However, current findings are limited due to methodological limitations and the over-reliance on mixed sample populations (De la Rie *et al.*, 2006). In her review, Bell (2003) highlighted a range of methodological problems in the existing literature including poor sampling, the use of non-standardised measures of satisfaction and the employment of retrospective designs. The use of mixed eating disorder samples is also problematic, as differences in perceptions of treatment may exist between those with specific eating disorder diagnoses.

Despite poor treatment outcomes, there is a distinct lack of qualitative research on perceptions of treatment for AN. The research to date remains fragmented and does not represent a succinct body of evidence. Previous reviews of qualitative research of treatment perceptions for eating disorders (e.g. Bell, 2003; Espindola & Blay, 2009) have not focussed on solely on studies specific to AN. In Bell (2003), 11 out of 23 papers were qualitative studies of patients' with AN, while the remaining

studies focussed on patients with bulimia nervosa, mixed eating disorder populations and families/carers. Similarly, Espindola and Blay included 5 studies which included mixed eating disorder samples.

Considering the above findings, there is a need to summarise the existing qualitative research on the views of patients with AN in order to develop our understanding of treatment needs and expectations for this specific clinical group. Such understanding may highlight reasons behind non-adherence and/or drop out rates and lead to the development of more acceptable and effective interventions (Escobar-Koch *et al.*, 2010). The purpose of the current paper is to systematically review treatment perceptions of patients with AN. Specifically, this review will summarise and critically evaluate the existing qualitative literature exploring treatment perceptions of AN from the patients' perspectives and outline clinical and research implications. The current paper expands on the previous reviews by systematically reviewing the most recent qualitative research in this area and providing in-depth methodological appraisal of the qualitative studies.

## **METHOD**

### **Search strategy**

Studies were identified using a search of the following electronic databases: PubMed, EMBASE, PsycINFO and CINAHL (1990-2010). The initial search was carried out in March 2010 and an updated search was conducted in August 2010 to incorporate any recently published studies. The research used the following key words in combination as search terms: “eating disorders” OR “anorexia” OR “anorexia nervosa” AND “qualitative” OR “qualitative study” OR “qualitative research” OR “experiences” OR “views” OR “perceptions” OR “treatment satisfaction” OR “services”. Additional studies were located from manual searches of previous reviews and article references. Hand searching of key eating disorder and health journals (e.g. European Eating Disorders Review, International Journal of Eating Disorders & Journal of Health Psychology) which have published qualitative papers relating to the nature of the research was also undertaken. Principal authors of published papers in this area were also contacted for unpublished studies.

### **Inclusion criteria**

The method followed the guidelines for systematic reviews by Droogan and Cullum (1998) adjusted to the purpose of the present review paper. These guidelines have been used in a number of previous reviews of different areas including cancer (Chouliara, Kearney, Stott, Molassiotis & Miller, 2004), trauma (Karatzias, Chouliara, Maxton, Freer & Power, 2007) and childhood sexual abuse (Chouliara, Hutchinson & Karatzias, 2009). Only studies of qualitative or mixed designs were included if they fulfilled the following inclusion criteria. Existing quantitative research has predominately focussed on treatment outcomes in AN (e.g. Collin, Power, Karatzias, Grierson & Yellowless,

2010) or has utilised satisfaction questionnaires with mixed eating disorder samples and not specifically with patients' with AN (e.g. De la Rie *et al.*, 2006; De la Rie *et al.*, 2008). The inclusion of quantitative treatment satisfaction studies of mixed eating disorder samples may have increased the heterogeneity of results as differences in perceptions of treatment may exist between those with specific eating disorder diagnoses.

- (a) Studies were published in peer reviewed journals after 1990. This timeframe was chosen due to the introduction of The Community Care Act in 1990 which marked the development of key patient and public involvement policies in health and social care (DOH, 2004).
- (b) Studies were published in English. (Due to limited resources for the translation of studies).
- (c) Studies had to report primary data. Those that were solely review articles were excluded.
- (d) Studies had to include individuals with a diagnosis of AN, independent of illness severity, who had undergone or were currently involved in treatment. The definition of treatment included any form of inpatient and/or outpatient treatment (e.g. specialist, generic, private).
- (e) Studies had to report qualitative research of individuals' experiences of treatment in relation to AN.
- (f) Studies included adolescents and/or adults only.

A total of 693 studies were initially retrieved and screened according to the review criteria. From these 75 required further scrutiny to determine whether they met

the review criteria. Finally, 14 were reviewed. Sixty-one were excluded for the following reasons: a) they were not primary data studies (n=3), b) did not focus on adolescents or adults (n=3), c) did not focus on patients' perceptions of treatment (n=33), d) did not include patients with AN or included patients with AN alongside patients with Bulimia Nervosa (BN) and Eating Disorders Not Otherwise Specified (EDNOS) as part of a mixed sample (n= 21) and e) only an abstract could be located (n=1). The author of the research abstract could not be contacted.

### **Methodological quality criteria**

The current review used a quality appraisal checklist incorporating ten evaluative criteria from existing quality frameworks (Critical Appraisal Skills Programme (CASP) 2006; Mays & Pope, 2000). Study quality was appraised on the following criteria: (1) presence of a clear aim; (2) appropriateness of qualitative methodology; (3) clear description of context/setting; (4) evidence of purposeful sampling and definition of sample characteristics; (5) systematic account of data collection methods; (6) systematic account of data analysis; (7) appropriateness of interpretations; (8) evidence of credibility checks; (9) evidence of reflexivity and (10) level of contribution to existing knowledge.

Each criterion was assessed following outcome ratings as used by Cesario, Morin and Santa-Donato (2001) and the Scottish Intercollegiate Guidelines Network (SIGN). Dimensions were given a score of 3 points if well addressed, 2 points if adequately addressed, 1 point if poorly addressed and 0 points if not reported. A total quality score was developed by summing scores of each criterion for a possible score of 0-30. Studies given a grade of “++” had a total score of 22.5-30. This indicated that studies met 75 % to 100% of the maximum total score and had a low risk of bias.

Studies given a grade of “+” had a total score of 15-22.4. This indicated that 50% to 74% of the maximum total score was met and that studies had a moderate risk of bias. Studies assigned a grade of “-” had a total score of less than 15. This indicated that studies met less than 50% of the maximum total score and had a high risk of bias.

All papers were rated independently by two reviewers. There was exact agreement on 74% (103/140) of the methodological criteria. The reviewers differed by 1 point on 24% (34/140) at the level of each of the criteria and by 2 points on 2% (3/140) of the criteria. There was agreement on the overall categorisation of 13 out of the 14 (93%) reviewed studies. Reviewers differed by one point on the total score of the remaining study, which led to a discrepancy in the overall grade. A third reviewer independently reviewed 7 out of 14 papers including the study which had been graded differently, to verify the reliability of the ratings. The third reviewer rated the particular paper similar to the first reviewer and the paper was given the grade which reflected this agreed total score. Differences between ratings were discussed between the three reviewers and the final scores were agreed upon and amended where appropriate.

### **Data extraction and synthesis**

The main framework for data extraction was thematic. Information relating to the characteristics of the study (e.g. sampling and assessment method) was included for the quality appraisal process. Findings focused on highlighting the perceptions of service provision and the key aspects of the treatment process for AN.

There remains considerable debate regarding the synthesis of studies using different qualitative approaches within systematic reviews (Mays, Pope & Popay, 2005; Thomas & Harden, 2008). It remains unclear whether established methods such as meta-ethnography (Noblit & Hare, 1988) are able to synthesise all relevant qualitative

research or only those based on similar conceptual or theoretical frameworks (Dixon-Woods *et al.*, 2006). The choice of method is seen as dependent upon the review purpose and the nature of the qualitative findings across the studies (Sandelowski & Barroso, 2003). Integration of themes was based on previous literature with themes identified and refined through review of subsequent papers (Noyes & Popay, 2007). The included studies demonstrated different levels of interpretation of the findings and were too disparate to allow the use of methods such as meta-synthesis or meta-ethnography as outlined by Dixon, Fitzpatrick and Roberts (2001). As such, the findings were synthesised using narrative summary.

## **RESULTS**

Fourteen studies met the inclusion criteria. A synthesis of findings from the reviewed studies is presented. Results are organised in the areas of interest pertaining to patients' views and experiences of (1) professional practice, (2) treatment and (3) aspects of service provision. The framework for organising the results reflects the key aspects of the assessment of treatment quality, primarily evaluations of the process and structure of treatment and services, which has been highlighted in previous research (Donabedian, 1980; Newton, 2001).

### **Study characteristics**

A summary of the characteristics of the studies is presented in Table 1

**Table 1: Characteristics of studies of anorexia nervosa**

Author/ Country	Method	Sample Size (N)	Participants	Findings	Strengths	Limitations	Study Quality
1. Button & Warren (2001) (UK)	Semi-structured interview schedule CEDRI, LIFE, SELF- GRID, RSE, SCL- 90-R, EDI	36 (45.6% response rate)	Patients (mean age = 27.9 years) who had received treatment between 1986–1993. Interviewed 7.5 years after presentation to specialist eating disorder service.	33.3% found treatment broadly helpful. Staff attitudes/overemphasis on weight unhelpful and psychotherapy helpful. Key themes: need for greater awareness and accessibility, importance of therapeutic alliance and self-motivation.	Focus on personal experience and treatment. Treatment context and sample clearly defined.	Retrospective design with limited response rate. Approach to data collection and analysis of qualitative data not explicitly stated. Limited reference to credibility checks.	+
2. Colton & Pistrang (2004) (UK)	Semi-structured interview, SCRCQ	19	Adolescents (mean age=15.4 years) in two inpatient eating disorder units.	Key themes: motivation for treatment important, peers provided support but increased distress. Recognition of individuality and collaboration by staff as helpful.	Focus on views of treatment. Sample and analysis clearly defined. Triangulation and credibility checks used. Excerpts provided.	Ill-defined treatment context. Questionnaire not validated. Generalisability of findings.	++
3. Darcy <i>et</i> <i>al</i> (2010) (USA)	Semi-structured interview or focus groups. EDE-Q, ANSOCQ, EDQOL	20	Patients (mean age = 29.3 years) recruited from community sources and internet postings.	Diversity of participant goals for treatment, 20% rated being listened to as important. Unsuitable treatment settings, poor therapeutic relationship and treatment inflexibility contributed to drop-out rates.	Clear aim, reference to triangulation and credibility checks. Excerpts provided.	Poorly described treatment context. Ill defined sample and recruitment. Data analysis not explicitly stated. No reference to reflexivity.	–
4. Evjors <i>et</i> <i>al</i> (2003) (UK)	Semi-structured interview schedule and narrative account	8	Patients (22-43 years) who had withdrawn from treatment from a local specialist eating disorder service.	Key themes: poor treatment collaboration, focus on symptoms reinforced AN, treatment timing and clinical context. All factors increased feelings of lack of control.	Clear aims with focus on treatment. Appropriate methodology. Sampling and context explicit. Triangulation used.	Small sample size. Theoretical framework and approach to data analysis not explicitly stated. Lack of reflexivity.	++



**Table 1: Characteristics of studies of anorexia nervosa**

Author/ Country	Method	Sample Size (N)	Participants	Findings	Strengths	Limitations	Study Quality
5. Federici & Kaplan (2008) (Canada)	Semi- structured interview schedule, SCID, EDE	15  8 relapsed 7 recovered	Patients (18 + years) at 1 year post- treatment from a general hospital as inpatient/intensive outpatient.	Recovery factors: internal motivation, specific interventions and supportive relationships. Relapse factors: reluctance to change, inability to tolerate negative emotions, low- esteem, inadequate support, inflexible f/up care and behavioural treatment focus.	Clear aim, appropriate methodology and context explicit. Clear data collection and analysis.	Focus not specifically on treatment. Retrospective design. Sampling bias. No respondent validation.	++
6. Griffiths <i>et al</i> (1996) (Australia)	Questionnaire – consumer survey	48	Inpatients (mean age = 18.3 years) at two psychiatric hospitals.	All but 1 patient found bed- rest unpleasant. Main complaints were of boredom, restriction and isolation. Perceptions changed according to stage of treatment.	Focus on view of specific treatment intervention.	Not views of general treatment, sample and treatment context ill defined, data analysis not explicit.	–
7. Hsu <i>et al</i> (1992) (UK)	Semi- structured interview schedule, EDI, HDRS, SCL- 90, MOC, SAS, CCEI	6	Patients (34-39 years) who had treatment between 1965-1973.	2 patients perceived treatment as frightening, 3 patients perceived inpatient treatment as ineffective. 2 patients felt outpatient treatment helpful due to therapeutic relationship.	Clear focus on treatment and recovery. Context and sampling described.	Retrospective case study design. No reference to data analysis approach, no reference to credibility checks or reflexivity.	–
8. Offord <i>et al</i> (2006) (UK)	Semi- structured interview schedule	7	Adolescents (16-23 years) with previous treatment in general adolescent psychiatric inpatient units. Interviewed 2-5 years post treatment.	Key themes: removal from normality, treated as “anorexic” versus individual, emotional issues seen as more important. Collaboration, individual approach and peer relationships helpful.	Focus on views of treatment. Ethical issues considered. Clear methodology and approach to data analysis. Member checking. Excerpts provided.	Retrospective, selection of sample and treatment context not explicit.	++

**Table 1: Characteristics of studies of anorexia nervosa**

<b>Author/ Country</b>	<b>Method</b>	<b>Sample size (N)</b>	<b>Participants</b>	<b>Findings</b>	<b>Strengths</b>	<b>Limitations</b>	<b>Study Quality</b>
9. Tan <i>et al</i> (2003) (UK)	Semi-structured interview schedule	10	Adolescents (13-21 years old) and parents. 50% had experienced or were currently under compulsory treatment orders.	Having control in treatment crucial for treatment acceptability. Need for support to engage in treatment. Compulsory treatment acceptable if at risk of death. Varied views regarding competence to make treatment decisions.	Clear aims and appropriate methodology. Sample defined. Use of excerpts. Reference to negative cases/alternative views.	Data collection and analysis ill defined. No reference to credibility checks or reflexivity. Ability to generalise findings are limited.	+
10. Tan <i>et al</i> (2010) (UK)	Semi-structured interview schedule	29	Patients (mean age = 18.1 years) from 4 different treatment centres. 8 inpatients, 18 day patients/ outpatients, 1 waiting treatment and 2 discharged.	Compulsive treatment acceptable to prevent death. Informal rather than legal detention preferred. Choice less important than staff relationships. Staff use of restrictions seen as problematic.	Focus on treatment acceptability of specific treatment aspect, sample from different centres, excerpts provided.	No focus on general treatment views, data collection and analysis not explicit. No evidence of reflexivity.	+
11. Tierney (2008) (UK)	Semi-structured interview schedule	10	Adolescents (mean age = 17 years) with current treatment/less than 3 years discharge. 6 from specialist psychiatric unit. 4 from local self-group.	Key themes: motivation important for outcome, difficulties accessing services. Experienced staff, psychological care and non-professional support seen as helpful. Treatment too focussed on physical restoration as unhelpful.	Focus on views of treatment. Defined sample with reference to saturation. References to reflexivity. Data collection clear and used pilot interviews.	Treatment context ill defined and possible selection/respondent bias. Partially retrospective. Data analysis not detailed with limited reference to credibility assurance.	++

**Table 1: Characteristics of studies of anorexia nervosa**

Author/ Country	Method	Sample size (N)	Participants	Findings	Strengths	Limitations	Study Quality
12. Tozzi <i>et al</i> (2003) (New Zealand)	Semi-structured interview schedule	69	Adult females (mean age = 32.3 years) who were referred to an eating disorders service between 1981-1984.	Therapy and supportive relationships with a therapist viewed as important for recovery. Few patients viewed medication as helpful other than for co-morbid mood difficulties.	Appropriate methodology and clear aim. Sample and data collection procedure adequately described.	Retrospective design, focussed on recovery than treatment. Treatment context ill-defined. Data analysis not explicit. Limited reference to patient excerpts.	++
13. Van Ommen <i>et al</i> (2009) (Netherlands)	Semi-structured interview schedule	13	Adolescents (13-17 years) post-discharge from specialist eating disorders inpatient service.	Initial structured, firm approach with consistent physical presence seen as necessary. Staff attitudes important. Being alongside peers also facilitated recovery.	Appropriate methodology. Clearly defined treatment context and sampling. Clear data collection and analysis with reference to patient excerpts. Reference to credibility methods.	Aim focused on nursing care in relation to body weight. Retrospective design.	++
14. Whitney <i>et al</i> (2008) (UK)	Written feedback letter of treatment experience	19	Female patients (mean age = 30.3 years) currently receiving inpatient treatment in eating disorders unit.	Essential that treatment given at right time when patient receptive and motivated to change. Specific therapy approach seen as less intense and complimented other treatments. Therapeutic relationship seen as necessary for treatment satisfaction.	Appropriate methodology. Clearly defined treatment context and sample with reference to saturation. Explicit data analysis and use of triangulation methods. Patient excerpts used.	Focused on specific treatment approach. Risk of result bias. Limited generalisability of results.	++

**List of Table Abbreviations.** CEDRI: Clinical Eating Disorders Rating Instrument; LIFE: Longitudinal Interval Follow-up Evaluation; RSE: Rosenberg Self-Esteem Scale; SCL-90-R: Symptom Checklist Revised; EDI: Eating Disorders Inventory; SCRCQ: Stage of Change and Readiness to Change Questionnaire; EDE-Q: Eating Disorder Examination Questionnaire; ANSOCQ: Anorexia Nervosa Stages of Change Questionnaire; EDQOL: Eating Disorder Quality of Life Instrument; SCID: Structured Clinical Interview for DSM Disorders; EDE: Eating Disorder Examination; HDRS: Hamilton Depression Rating Scale; MOC: Maudsley Obsessive Compulsive Inventory; SAS: Social Adjustment Scale; CCEI: Crown Crisp Experiential Index.

Of the 14 studies reviewed, eleven used semi-structured interviews, two used open-ended surveys/questionnaires and one used a combination of semi-structured interviews and focus groups. Four studies used additional standardised questionnaires to measure symptom severity. A range of qualitative approaches were utilised with four of the reviewed studies using grounded theory, two using interpretative phenomenological analysis, five studies made reference to thematic analysis and three studies did not specify the approach employed.

Six of the reviewed studies focussed on adolescent populations and eight studies used adult participants. The number of participants varied between 6 (Hsu, Crisp & Callender, 1992) and 69 (Tozzi, Sullivan, Fear, McKenzie & Bulik, 2003). Twelve studies used only female participants, while two studies included males (Button & Warren, 2001; Griffiths *et al.*, 1996). Six studies provided participants' Body Mass Indices (BMIs) at the time of data collection (Button & Warren, 2001; Federici & Kaplan, 2008; Griffiths *et al.*, 1996; Tan, Stewart, Fitzpatrick & Hope, 2010; Tozzi *et al.*, 2003; Whitney *et al.*, 2008). The majority of studies did not report additional demographic information such as ethnicity or educational/occupational background.

Recruitment differed across the 14 studies with five recruiting participants from inpatient units (Colton & Pistrang, 2004; Griffiths *et al.*, 1996; Tierney, 2008; Van Ommen, Meerwijk, Kars, Van Elberg & Van Meijel, 2009; Whitney, Easter, Tchanturia, 2008) five from outpatient services (Button & Warren, 2001; Eviors, Button, Warner & Turner, 2003; Hsu *et al.*, 1992; Offord *et al.*, 2006; Tozzi *et al.*, 2003), two from both inpatient and outpatient units (Federici & Kaplan, 2008; Tan *et al.*, 2010), one from community sources and internet postings (Darcy *et al.*, 2010) and one study did not specify the recruitment approach (Tan, Hope, Stewart & Fitzpatrick,

2003). Out of the 14 studies only three studies recruited participants from specialist eating disorders treatment settings (Colton & Pistrang, 2004; Van Ommen *et al.*, 2009; Whitney *et al.*, 2008). Nine studies were based in the UK, one in the USA, one in the Netherlands, one in New Zealand, one in Canada and one in Australia.

### **Quality ratings**

The quality ratings for the 14 studies are presented in Table 2. Ratings ranged from 11 (Hsu *et al.*, 1990) to 26 (Federici & Kaplan, 2008; Van Ommen *et al.*, 2009; Whitney *et al.*, 2008) out of a possible total score of 30. Seven studies had a total score of 75% or more and were assessed to be of a good methodological quality (Colton & Pistrang, 2004; Eviors *et al.*, 2003; Federici & Kaplan, 2008; Offord *et al.*, 2006; Tierney, 2008; Van Ommen *et al.*, 2009; Whitney *et al.*, 2008). Except for three studies (Darcy *et al.*, 2010; Griffiths *et al.*, 1996; Hsu *et al.*, 1990) the remaining studies had a total score of 50% or more and were of an average methodological quality (Button & Warren, 2001; Tan *et al.*, 2003; Tan *et al.*, 2010; Tozzi *et al.*, 2003).

Table 2. Quality appraisal of included studies

Studies	Quality Criteria										Total Score	Overall Rating
	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)		
1. Button & Warren (2001)	3	2	3	3	2	1	2	1	0	2	19/30	+
2. Colton & Pistrang (2004)	3	3	1	3	2	3	3	3	1	3	25/30	++
3. Darcy <i>et al</i> (2010)	2	2	0	1	1	1	2	2	0	2	13/30	-
4. Eviors <i>et al</i> (2003)	3	3	3	3	3	2	3	2	0	2	25/30	++
5. Federici & Kaplan (2008)	3	3	3	2	3	3	3	3	0	2	26/30	++
6. Griffiths (1996)	2	1	1	2	2	1	1	0	0	2	12/30	-
7. Hsu <i>et al</i> (1990)	2	2	2	2	1	0	1	0	0	1	11/30	-
8. Offord <i>et al</i> (2006)	3	3	1	1	2	3	3	3	2	3	25/30	++
9. Tan <i>et al</i> (2003)	2	3	3	2	1	1	3	0	0	2	17/30	+
10. Tan <i>et al</i> (2010)	3	2	3	3	1	1	2	0	0	2	17/30	+
11. Tierney (2008)	3	3	2	3	3	2	3	1	1	2	23/30	+
12. Tozzi <i>et al</i> (2003)	2	3	1	2	2	1	1	1	0	2	15/30	+
13. Van Ommen <i>et al</i> (2009)	3	3	2	3	3	3	3	3	0	3	26/30	++
14. Whitney <i>et al</i> (2008)	3	3	1	3	3	3	3	2	0	3	26/30	++

(1) The study has a clear statement of aims/objectives.

(2) The qualitative research design is clear and appropriate for the research aims.

(3) Clear description of the context or setting is adequately described so the reader can relate the findings to other settings.

(4) Sampling was suitable and participant characteristics were clearly described. Clear description of how sample selected and why.

(5) The study provided a clear and systematic account of data collection methods.

(6) The study demonstrated a descriptive and systematic account of data analysis and included or referred to a clear data audit trail.

(7) The results were clearly supported by the data.

(8) Steps taken to ensure credibility were used (e.g. triangulation, respondent validation, negative cases, others involved in analysis).

(9) Reflexivity was demonstrated (personal biases, effects of personal characteristics, prior assumptions, relationship between researcher and subjects should be identified).

(10) The study contributed to existing knowledge/populations, while outlining its limitations.

3: Well addressed, 2: Adequately addressed, 1: Poorly addressed, 0: Not reported/not applicable.

## **Views and experiences of professional practice**

Twelve (85.7%) of the studies reviewed made reference to experiences of professional practice and support. Some of the reviewed studies (e.g. Button & Warren, 2001; Darcy *et al.*, 2010; Van Ommen *et al.*, 2009; Whitney *et al.*, 2008) presented only positive or negative experiences increasing the risk of providing one-sided accounts of professional practice. Overall, several studies reported the importance and value of non-specific therapeutic skills, including being non-judgemental, having good communication skills, being available, engaging well with patients and the development of a supportive working relationship (Colton & Pistrang, 2004; Tierney, 2008; Van Ommen *et al.*, 2009; Whitney *et al.*, 2008). Specifically, Van Ommen *et al.* (2009) reported professional attitudes such as reliability, respect for individuals, physical and emotional availability, and firmness as essential for normalising eating patterns and improving body weight. Patients referred to the development of a trusting therapeutic relationship that enabled discussion of difficult topics and the pursuit of goals of post-discharge. Nevertheless, information was obtained retrospectively and was focussed only on nursing care in relation to body weight limiting the ability to generalise findings. Conversely, in Darcy *et al.* (2010), approximately half of participants reported dropping out of therapy due to patient-therapist factors including feeling forced into making changes. Although this study explored treatment engagement factors, the findings were limited due to several methodological weaknesses including retrospective design, poorly defined context and selection of participants from undefined community and internet sources.

Several studies identified the need for greater professional expertise, highlighting patient concerns about the standard of current professional knowledge and clinical practice (Colton & Pistrang, 2004; Offord *et al.*, 2006; Tierney, 2008). In

Tierney (2008), patients perceived health professionals with greater expertise in working with individuals with AN as more prepared for patient attempts to falsify their weight. Conversely, a lack of specialist knowledge led to feelings of increased professional insensitivity and reduced support. However, the sample consisted of adolescents recruited from generic inpatient psychiatric units. Non-specialist treatment settings are likely to differ vastly from the treatment and level of support provided from specialist units for eating disorders. In two studies (Colton & Pistrang, 2004; Offord *et al.*, 2006) patients' perceptions of being labelled by professionals as "anorexics" rather than as individuals led to feelings of frustration, reduced trust in professionals and treatment engagement difficulties. Although both studies used rigorous and explicit analysis, the samples consisted only of adolescents, which might contribute to a skewed view of therapy and its impact on self-esteem development. The retrospective designs and partial description of the treatment context limit the findings.

### **Views and experiences of treatment**

Previous studies have highlighted aspects of treatment that are seen as important by patients with AN for treatment engagement, satisfaction and recovery. Seven of the reviewed studies (50%) noted that patients perceived treatments as helpful to recovery if they addressed underlying psychological issues in addition to physical symptoms (Button & Warren, 2001; Colton & Pistrang, 2004; Eviors *et al.*, 2003; Federici & Kaplan, 2008; Offord *et al.*, 2006; Tierney, 2008; Whitney *et al.*, 2008). In contrast, the neglect of psychological issues in treatment led to treatment engagement difficulties and patients feeling unskilled and at risk of relapse post-discharge (Eviors, *et al.*, 2003; Federici & Kaplan, 2008; Tierney, 2008). Two of these studies (Eviors *et al.*, 2003; Federici & Kaplan, 2008) included patients who had chosen to withdraw from treatment



or who had relapsed following treatment. The majority of the patients continued to fulfil diagnostic criteria for AN at interview, which may have led them to perceive their treatment more negatively than those who had recovered. Specifically in Federici and Kaplan (2008), relapsed patients were more ambivalent to make behaviour changes throughout treatment, possibly impacting their ability to sustain progress following discharge regardless of the intervention.

In six (42.9%) studies, patients specifically highlighted preferences for non-medical interventions such as psychological therapy (Button & Warren, 2001; Colton & Pistrang, 2004; Darcy *et al.*, 2010; Hsu *et al.*, 1992; Offord *et al.*, 2006; Tierney, 2008). However, there was little reference to the description of the treatment context in these studies and it was unclear whether the reports of the imbalance of treatment components were accurate. Individual therapy and specific treatment components including psycho-education, identifying dysfunctional thoughts, behavioural strategies such as diary keeping were valued by patients (Button & Warren, 2001; Offord *et al.*, 2006). Drug treatments were seen as useful for addressing co-morbid mood difficulties but not for the improvement of core eating disorder psychopathology (Button & Warren, 2001). However, in the study by Button and Warren (2001), participants were recruited approximately seven years after presentation to the service and it was unclear whether they still remained in treatment. This sampling strategy is likely to result in selection bias and questions the validity of recalled treatment experiences. In addition, the researchers did not provide a detailed account of the qualitative framework underlying data collection procedures and analysis.

The importance of patient involvement within treatment was also reported. Findings by Offord *et al.* (2006), highlighted that the following key practices contributed to patient feelings of empowerment: the provision of clear information and treatment

goals, meal preparation work, plotting personal weight charts and being given more freedom. According to Van Ommen *et al* (2009) patients felt the opportunity for collaboration in their treatment plan enhanced the therapeutic environment and increased feelings of control. Although this study provided systematic accounts of data collection and analysis, it employed a retrospective design using recovered patients, resulting in the potential recall bias of positive experiences. In contrast, restrictive and compulsory interventions were seen as unhelpful (Colton & Pistrang, 2004; Darcy *et al.*, 2010; Eviors *et al.*, 2003; Griffiths *et al.*, 1998; Offord *et al*, 2006; Tan *et al.*, 2003; Tan *et al.*, 2010). According to Tan *et al* (2010), patients only regarded compulsory treatment practices as acceptable as a life saving measure. Griffiths *et al* (1996) found approximately half of inpatients receiving compulsory bed-rest, viewed the intervention as unpleasant and unhelpful with the main complaints relating to boredom and isolation. While this study sought the views of current inpatients, the treatment context was poorly defined, limiting the findings. In addition, the researchers did not provide a detailed account of the qualitative framework underlying the data analysis and the presentation of findings were based on descriptive statistics.

### **Views and experiences of service provision**

Only six (42.9%) of the reviewed studies explored experiences of service provision in relation to accessibility, setting and transition (Button & Warren, 2001; Colton & Pistrang, 2004; Darcy *et al.*, 2010; Eviors *et al.*, 2003; Offord *et al*. 2006; Tierney, 2008). However, these studies did not focus on aspects of service provision exclusively. In Tierney (2008), the lack of knowledge and expertise of general practitioners prevented early diagnosis and led to delays in the access of specialist treatment. Patients reported a lack of appropriate services, with initial referrals made to generic services

with non-specialist clinical staff. Access to specialist services was only available when symptoms became severe and prior treatment had failed. However, participants in this study were not comprised exclusively of current patients and only one patient had experience of specialist eating disorder services. This may either reflect the reported accessibility issues or that the sample consisted of patients with lower levels of illness severity. In addition, recruitment was through clinical staff at a general psychiatric adolescent service. Such sampling might have resulted in selection bias and limits the ability to generalise the findings, particularly to adult populations. In addition, only one study highlighted patients' views of service transition. According to Offord *et al* (2006), patients felt significant differences between hospital treatment structure and life post-discharge. Planned transitions and continued support from specialist services following discharge were seen as essential to prevent relapse. In contrast, unplanned transitions or infrequent post-discharge support were viewed negatively.

In addition to poor accessibility, patients were found to be dissatisfied with treatment settings. Patients preferred non-healthcare service settings with hospital and psychiatric settings contributing to feelings of stigma and lowered self-esteem (Button & Warren, 2001; Eviors *et al.*, 2003). Patients reported being admitted to places that were inappropriate for their needs such as general wards and living alongside patients of different ages, leading to drop-out (Darcy *et al.*, 2010). Only three studies (Colton & Pistrang, 2004; Offord *et al.*, 2006; Tierney, 2008) explored views of receiving treatment alongside other patients' with eating disorders. Patient perceptions of helpful aspects included the provision of additional peer support, learning positive coping skills and reducing feelings of isolation. In contrast, patient perceptions of unhelpful aspects included learning maladaptive behaviours, feelings of competition and increased levels of distress. While these three studies demonstrated evidence of rigorous analysis,

samples consisted of female adolescents and the treatment context was poorly described, thereby limiting the generalisation of the findings.

### **Limitations of existing literature**

Despite the majority of the reviewed studies demonstrating average to good overall methodological quality, a number of methodological limitations were identified. Firstly, most studies did not provide clear descriptions of the sample and treatment contexts. Descriptions of participant demographics such as ethnicity, socio-economic status, severity of illness and treatment history were limited or not provided. Similarly, the description of the treatment programmes and settings including the structure, delivery and content of treatment modalities were inadequate. Treatment modalities, which are broadly described as “psychological therapy” or “medical interventions”, may represent a variety of different approaches and lead to misinterpretations (Bell, 2003). This lack of description makes it difficult to assess the patient and treatment variables that contribute to treatment perceptions and limits the generalisability of the findings.

Secondly, sampling and recruitment strategies led to the possibility of selection bias and skewed views of treatment. Participants were recruited by various methods and settings including community groups, internet postings and through clinical staff from treatment centres. Some studies employed a retrospective design or focussed on patients who had dropped out of treatment or had relapsed. Participants’ views of therapy may be influenced by their symptom severity, stage in treatment and recovery and treatment outcomes. Clinical staff might have approached patients likely to provide positive evaluations or with better treatment outcomes. Similarly, negative views may have been gathered from patients who had relapsed, had poor motivation to change or were in the early stages of treatment. In addition, the retrospective design

may have led to recall inaccuracies influenced by current health status or memory recall abilities.

Finally, the description of data collection procedures and analysis based on qualitative approaches were poorly defined. Some studies presented descriptive results or provided limited examples of the data to illustrate their analytic process. The use of credibility methods for ensuring methodological rigor such as negative case analysis, respondent validation, triangulation or multiple reviewers during data analysis was limited or absent. In addition, only three studies (Colton & Pistrang, 2004; Offord *et al.*, 2006; Tierney, 2008) made reference to methods of reflexivity. Even in these studies, the theoretical orientations, values and assumptions of the researchers were poorly defined, limiting the consideration of alternative interpretations of the data.

## **DISCUSSION**

This systematic review identified 14 papers which contained data on patients' perceptions of particular aspects of treatment quality for AN. Findings suggest patients' experiences and evaluations of treatment quality are variable. Valued aspects of treatment quality include supportive therapeutic relationships, being viewed as an individual and holistic treatment approaches which provide opportunities for patient collaboration. In contrast, concerns were raised in relation to significant barriers to the accessibility of specialist care, poor early diagnosis and the limited knowledge and expertise of some health professionals about eating difficulties. Treatment which focussed primarily on weight restoration or medical interventions, at the expense of addressing underlying issues was negatively perceived by patients. In addition, concerns were raised about the attitudes and lack of knowledge of staff who had limited or no experience in working with individuals with AN. However, the generalisability of these findings is restricted by significant methodological limitations in the current literature.

### **Clinical implications**

Findings from this review highlight the importance of a supportive therapeutic relationship in treatment, with value placed on non-specific therapeutic elements such as sensitivity, understanding and collaboration. Staff expertise in the treatment of eating disorders was also seen as essential in the provision of treatment, which acknowledged the individuality of patients and contributed to feelings of acceptance. However, a number of patients reported negative treatment experiences in relation to the attitudes and limited expertise of health professionals. An awareness of these views may help health professionals to review current working practices and help to address existing treatment difficulties. While acknowledging the contribution of patient characteristics in

treatment difficulties, there is a continued need for health professionals to develop specific clinical competencies and knowledge in working with individuals with AN to enable successful treatment outcomes (NICE, 2004).

In Reid, Williams and Burr (2010), health professionals providing care to patients with eating disorders reported their level of training and knowledge about eating disorders as inadequate. Lack of training led to feelings of professional incompetency and frustration, impacting negatively on the therapeutic process. The emphasis placed on the therapeutic relationship suggests health professionals need to reconsider the importance of interpersonal skills as an active medium for promoting recovery (Chouliara *et al.*, 2009). Recent literature has shown that patient-centred and interpersonal skills promote patient satisfaction, trust and effective treatment outcomes (Fuentes, Boylan & Fontanella, 2009; Kaplan & Garfinkel, 1999; Mostow *et al.*, 2010). In addition to specialist training, attention to relational models in clinical practice and training may equip health professionals with skills, which help to build patient trust in treatment. As highlighted in a previous review by Espindola and Blay (2009), false assumptions and negative attitudes of staff can also influence treatment outcome. Continuous reflection on clinical practice and personal attitudes towards patients with AN is therefore necessary to facilitate the therapeutic process.

As in previous reviews (Bell, 2003; Espindola & Blay, 2009), patients valued psychological therapy over medical interventions. Psychological therapy was seen as important to enable greater understanding of the issues underlying their condition and to identify practical coping strategies to reduce the risk of future relapse. Restrictive components of treatment were negatively viewed and only perceived as tolerable if facilitated through a supportive therapist or if an individual was at risk of dying. In contrast, collaborative treatment goals promoted recovery and treatment satisfaction.

Findings suggest a need to ensure the balance of the treatment focus on both physical restoration and the psychological and emotional elements underlying the condition. The neglect of psychological issues can increase patient frustration and impact upon the therapeutic process (Espindola & Blay, 2009). There is an implicit need for health professionals to adopt psychological models of working to allow for greater patient collaboration within treatment and to enable patients to develop long-term coping skills. The implementation of negatively viewed but essential aspects of treatment, such as nutritional interventions, may be helped by allowing for patient collaboration and control in the designation of related treatment goals.

The findings also highlighted patients' concerns regarding the poor accessibility of care due to the restricted availability of specialist ED services, delayed diagnosis and the limited knowledge and expertise of general practitioners. Patients expressed the importance of acceptable treatment locations and the need for post-treatment continuity of care following transitions between and from services. Interestingly, in Reid *et al* (2010) health professionals also acknowledged the current existing difficulties relating to referral pathways, treatment settings and the availability of specialist services. In particular, health professionals highlighted the need for specialist services, reporting the inappropriateness of generic service settings due to limitations in expertise and capacity. Given these reports, training and consultations with specialist services for general practitioners may lead to an improved knowledge base and improved patient management. It is also clear there is great demand for community based specialist care with clear referral pathways and communications between different services to allow improved access for those who require outpatient care in the first instance or those transferring from other hospital settings. There is also a need for planned discharge and longer term care provision to sustain patient confidence and prevent relapse during



service transitions and post-discharge (Reid *et al.*, 2010). It is expected that such modifications will greatly improve patients' experience of services and treatment satisfaction.

### **Future research**

In light of the findings of this review, there remains a need for further qualitative studies to explore the views and experiences of patients with AN in regard to their treatment. Many issues remain unanswered by the reviewed literature including: (1) the perceptions and experiences of adults with AN in relation to specialist and generic treatment settings such as inpatient treatment, outpatient treatment and day-patient services; (2) adults' perceptions and experiences about specific treatment approaches for AN including those that inhibit recovery; (3) treatment experiences of patients with AN who have dropped out or relapsed from treatment; (4) the views and experiences of patients with AN regarding transitions between services and continuity of care post-discharge and finally (5) patients' views and experiences of treatment accessibility for specialist services for AN and other eating disorders. In addition, there is a need to identify the contribution of therapist variables in relation to treatment outcome and for further qualitative research into different health professionals' views and experiences of aspects of treatment for eating disorders.

Taking into account previous limitations, future studies should adopt transparent sampling methods providing clear descriptions of both participant samples and the treatment context. Studies should follow appropriate theoretical frameworks in the consideration of sample sizes, type of qualitative methodological approach and data collection procedures. Data collection and analysis should be explicitly described with reference to accepted credibility methods for ensuring the quality of the findings

including reflexivity, respondent validation, triangulation and peer review. These considerations will result in the development of a clearer understanding of the expectations and preferences of patients with AN, in terms of their treatment and service provision.

### **Study strengths and limitations**

The current review has a number of strengths and limitations. The first author carried out an in-depth literature search using different electronic databases, manual searching of journals and contacting authors for unpublished material. The review employed clear critical appraisal procedures and the studies were assessed by more than one assessor, demonstrating good reliability of ratings. The findings are also summarised around the following three main thematic areas: views and experiences of professional practice, treatment and service provision. This allowed for a clear and detailed synthesis of the research findings in light of the methodological variability.

Among its limitations is the difficulty in synthesising the existing evidence relating to patients' treatment experiences, which is characterised by a wide variability in research design and qualitative methodology. The assumption that qualitative studies of different theoretical approaches can be integrated may be questionable. Also, the review did not include articles published in languages other than English, which may have limited the number of studies included. However, it was felt that the inclusion of studies published in languages other than English may have increased the heterogeneity of the sample, making attempts to synthesise the research more difficult. The review also used a narrative summary approach to synthesise the evidence rather than more established methods such as meta-ethnography. However it was felt that the findings of the individual studies were too disparate to allow the use of these methods.

## **Conclusions**

Understanding the experiences of treatment for AN from the patient perspective may aid treatment effectiveness and satisfaction. This systematic review of current qualitative research demonstrates variable experiences of treatment and service provision of patients with AN. A supportive therapeutic relationship was seen as essential for promoting treatment acceptance and recovery. Non-specific therapeutic skills such as empathy increased feelings of self-worth. Patients' preferences for psychological therapy emphasise their need to address the emotional and psychological issues underlying their condition. In addition, psychological approaches were viewed as enabling patient collaboration in their treatment planning. However, significant patient concerns remain in relation to the current primary treatment focus of weight restoration and the regional inequities of the availability of specialist services. The limited expertise of some non-specialist health professionals led to difficulties with early diagnosis, treatment accessibility and treatment engagement. These findings suggest the need for health professionals to broaden their knowledge of eating disorder psychopathology, to consider relational models of working and the implementation of psychological approaches in clinical practice. In addition, there is an identified need for the increasing availability and accessibility of specialist services with improved care pathways and follow-up care. However, conclusions remain tentative, as they are drawn from a small body of selected qualitative evidence.

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## **2. THESIS AIMS**

### **2.1 Summary of systematic review**

The systematic review highlighted the need for further qualitative studies to explore the views and experiences of patients with anorexia nervosa (AN) in regard to their treatment, in order to improve treatment engagement, satisfaction and outcome for this clinical population. While the 14 reviewed studies provide information regarding patients' perceptions of aspects of treatment quality for AN, the findings are limited by a number of methodological weaknesses. Most of the reviewed studies did not provide clear descriptions of the samples and the treatment contexts including the content and delivery of treatment programmes. Over half of the studies employed a retrospective design, which may have led to recall inaccuracies. In addition, the description of data analysis was poorly defined and the use of methods for ensuring methodological rigor was limited.

More specifically, there remains a lack of qualitative research which provides a detailed understanding of the treatment perceptions and experiences of adults with AN in relation to specialist inpatient treatment settings. Seven of the reviewed studies described patients' perceptions of inpatient treatment and only three of these studies focussed on specialist inpatient treatment settings. Furthermore, only one study was based upon an adult sample however this was limited to experiences of a specific treatment modality.

## **2.2 Aims of current study**

Therefore, the current study seeks to build on the small number of qualitative studies in this area by being the first study of the researcher's knowledge to explore adult female patients' lived experiences of specialist inpatient treatment for AN. The current study aims to explore perceptions of the process of inpatient treatment for adult females with AN and to identify key aspects of treatment which may influence treatment engagement and recovery. The study was designed to recruit and interview participants who were actively receiving inpatient treatment to avoid recall inaccuracies associated with retrospective studies. The current qualitative study is not hypothesis driven and instead adopts an exploratory approach. It is hoped that the results will help to inform clinical practice and improve specialist inpatient service provision.

### **3. METHODOLOGY**

This chapter presents the research methodology and the consideration of the main ethical issues. The process of ensuring the quality of the current study is also outlined.

#### **3.1 Design**

The current study adopts a qualitative methodology using Interpretative Phenomenological Analysis (IPA) (Smith 1996; Smith & Osborn, 2003; Smith & Eatough, 2007) to explore the nature of adult female patients' lived experience of specialist inpatient treatment for anorexia nervosa (AN). The main aims were to provide a detailed description of the perceptions and meaning of inpatient treatment for female patients with AN and where they see themselves in the recovery process.

#### **3.2 Reflective prologue**

As a Trainee Clinical Psychologist working within a specialist outpatient eating disorders service, I, the researcher, had clinical experience working with patients with eating disorders and had developed links with inpatient services. I had worked with several patients with AN following transition from specialist inpatient services for eating disorders and had become aware of the poor response to treatment and increased risk of relapse following discharge. I recognised that there was a need for myself and other professionals in this area to develop a greater understanding of patients' experiences of the process of inpatient treatment for AN.

A small but growing body of research has explored patients' perceptions of AN and recovery (Darcy *et al.*, 2010; Federici & Kaplan, 2008; Hsu *et al.*, 1992; Tozzi *et al.*, 2003). Existing research in relation to treatment perceptions has primarily used

samples of individuals with a range of eating disorder diagnoses and has focussed on treatment satisfaction (De la Rie *et al.*, 2008; Swain-Campbell *et al.*, 2001). A small number of qualitative studies have specifically explored adolescents' experiences of treatment for AN (Colton & Pistrang, 2004; Offord *et al.*, 2006; Tierney, 2008). However, very little qualitative research has focussed on how adults with AN experience treatment.

Therefore, the current study aims to build on the existing research and develop a more in-depth understanding of adult female patients' lived experiences of the process of inpatient treatment for AN. I was interested in exploring patient perceptions regarding what it is like to undergo hospitalisation for their illness and the key factors of the treatment experience that may influence their process of recovery. I hope that the results will help to inform clinical knowledge and to develop service provision and treatment strategies that are better equipped to meet the support needs of patients undergoing inpatient treatment for AN.

I maintained a research journal throughout the research process. This contained reflections on the experience of the study, acknowledgement of pre-existing knowledge of the area, potential bias and influence.

### **3.3 Selection of a qualitative approach in the current study**

Qualitative research is concerned with how people experience and make sense of specific events in their lives. It allows for exploration of the meaning attributed to events to provide a rich description of the experience and acknowledges the active role

of the researcher within the research process (Willig, 2001). According to Radley (1999), the experience of health and illness is not an objective phenomenon, with growing attention focused on the contribution of patient perceptions in relation to health behaviours and treatment. The concepts of health and illness are dependent upon the individual's interpretation of their condition in relation to all aspects of their life. Furthermore, Radley (1999) emphasises that research exploring health perceptions needs to take into account the interaction of the researcher and the individual with the condition to acknowledge how this may influence the research process.

Hepworth (1994) highlighted the lack of qualitative research in eating disorders as a “weakness” in developing a greater understanding of the clinical needs of the population. More specifically, Colton and Pistrang (2004) suggest that to understand the variability of treatment effectiveness in eating disorders it is necessary to firstly explore patients' experiences of their illness and treatment. In addition, Black (1994) suggests that qualitative methods are appropriate for exploring sensitive and complex issues. The researcher adopted a qualitative approach in the current study as it provided an opportunity to listen to and understand female patients' experiences of inpatient treatment for AN.

### **3.4. Interpretative Phenomenological Analysis (IPA)**

According to Smith, Flowers and Larkin (2009), IPA is a qualitative approach informed by the underlying philosophical principles of phenomenology, hermeneutics and idiography. Phenomenological inquiry, developed from the work of Husserl (1925), is concerned with conscious reflection upon a particular experience. According



to Willig (2001), phenomenology proposes a subjective reality where understanding of the world is dependent upon the perceptions of the individual. IPA is derived from phenomenology in that it is concerned with how a participant reflects and derives meaning from a significant experience. IPA is also informed by hermeneutics in that it recognises the importance of an interpretative process. According to Smith *et al* (2009), IPA involves a “double hermeneutic”, where the participant is making sense of their experience and the researcher is trying to make sense of the participant’s conceptualisations. From this, IPA aims to provide an interpretation of the experience which is more detailed and reflective than the participant’s perceptions. However, IPA recognises that the level of interpretation by the researcher is “second-order” and is complicated by the researcher’s own preconceptions and experiences. It is therefore important that the researcher adopts a reflexive position (Willig, 2001). IPA is also centred within an idiographic level in that it is concerned with individual experience (Larkin, Watts & Clifton, 2006). It follows a process of comparing individual accounts of a particular experience to provide shared meanings of the experience.

Reid, Flowers and Larkin (2005) emphasise the application of IPA to understand the views of service users within healthcare services, highlighting its ability to integrate research and practice. Similarly, Smith *et al* (2009) highlight the growing use of IPA within health related research to examine patient experiences of health conditions and treatments at both an individual and generalised level. For example, IPA has been used to explore patient experiences of palliative care services (Jarrett *et al.*, 1999), chronic fatigue syndrome (Arroll & Senior, 2008), cancer (Chouliara & Kearney, 2007) and eating disorders (Colton & Pistrang, 2004; Federici & Kaplan, 2008).

### **3.5 Justification of IPA in the current study**

Whilst IPA was selected, the researcher also considered the following alternative approaches when devising the current study: Discourse Analysis and Grounded Theory.

Discourse Analysis proposes that conversation is a social action and is concerned with how individuals express views to achieve personal objectives within a specific social context. It explores the use and function of discursive resources within conversations to provide an understanding of how individuals construct their social reality (Willig, 2001). Discourse analysis challenges cognitivism and argues that individuals' accounts are dependent upon the context in which they are discussed (Willig, 2008). It was felt that Discourse Analysis was unsuitable in relation to the research aims of the current study, which focuses on individual perceptions and sense making of a particular lived experience. In contrast, IPA is concerned with cognitive processes and recognises that individuals' accounts of events are linked to their cognitive processes and emotional state (Smith & Osborn, 2008).

Grounded Theory involves the development of a theory which is "grounded" in the data through the construction of categories (Glaser & Strauss, 1967). The resulting theory then provides a framework for understanding the specific phenomenon (Willig, 2001). Grounded Theory shares analytical techniques with IPA such as using thematic analysis and begins with the analysis of individual cases to the integration of several accounts. While Grounded Theory is a more established methodology, its primary research aim is to construct an explanatory and theoretical account of a phenomenon in

relation to the data. Conversely, IPA adopts a discovery-oriented and phenomenological approach. The primary aim of IPA is to provide an in-depth description of the quality and texture of the individual's lived experience (Willig, 2001). Additionally, the application of IPA incorporates clear guidelines for the inexperienced qualitative researcher (Smith & Osborne, 2008).

The aim of the current study was to explore in detail the inpatient treatment experiences for adult females with AN. Therefore, IPA was selected as the best approach.

### **3.6 Ethical issues**

The research proposal for the study was initially reviewed and approved by the University of Edinburgh DClinPsychol Ethics committee. The study also received ethical approval from the local area NHS Medical Research Ethics Committee and NHS Research and Development Department (see Appendix 1). The study was informed by guidelines set out in the British Psychological Society's Good Practice Guidelines for the Conduct of Psychological Research within the NHS (British Psychological Society, 2005). Approval was also obtained from the hospital director of the eating disorder unit<sup>1</sup> (see Appendix 2).

The following sections summarise the main ethical issues arising from the study and the steps taken to address them.

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<sup>1</sup> The name of the specialist eating disorders inpatient unit where the current research was conducted is omitted in this thesis to protect the anonymity of participants.

### **3.6.1 Patient vulnerability and distress**

The researcher recognised from clinical experience that this was a potentially vulnerable population and liaised closely with clinical staff within the eating disorders unit to aid identification of patients who were too emotional or physically frail to participate. The development of inclusion/exclusion criteria in collaboration with clinical staff ensured that only patients who were medically stable and without acute distress were approached.

The researcher acknowledged that participants could experience a degree of distress should they decide to discuss difficult personal experiences relating to their condition. Procedures were put into place to minimise and manage emotional distress levels and these were outlined to patients within a Participant Information Sheet (see Appendix 3). The principles of sensitive interviewing for health care issues were followed at all times during data collection in order to minimise embarrassment and discomfort for participants (Price, 2004). Participants were informed that they were able to request breaks throughout the interview to minimise levels of fatigue and distress. Time was also allocated at the end of the interview to allow the participant to reflect on the interview process and to give the opportunity to ask questions about the study. Participants were also asked whether they wanted a summary of the study findings once completed. Additionally, participants were provided with a Debriefing handout (see Appendix 4) post completion of the interview, which included details of available resources for further information and support out-with the eating disorders unit.

If participants became distressed or disclosed issues that required further investigation during participation, the researcher informed identified members of the clinical team. This procedure is in line with Section 7.1 of the British Psychological Society's Code of Conduct, Ethical Principles and Guidelines (British Psychological Society, 2005). Limits to confidentiality were detailed within the Patient Information Sheet and discussed with participants prior to the commencement of each interview. A senior staff member from the hospital was identified as a named contact for patients who had concerns or grievances about the conduct of the study. This staff member was independent from the study.

### **3.6.2 Informed consent**

The recruitment process had been devised to allow participants to make their own choices regarding participation in a discreet manner. This enabled participants to feel in control. Past research indicates that this may be a significant issue for individuals with AN. Participants were given a Participant Information Sheet in advance of the study, providing an opportunity for them to read this in their own time and thus be able to ask questions about the study to aid their decision about participation. Written consent using a Participant Consent Form was obtained prior to the commencement of the interview (see Appendix 5). It was emphasised that participation/non-participation within the study was voluntary and would not affect their treatment or their relationship with staff members. It was emphasised that participation in the study would not lead to immediate changes in the service although it may help to inform future care. It was also made explicit that participants could withdraw from the study

at any point without providing a reason and that they could ask for their anonymised data to be deleted prior to being incorporated into the thesis and further publications.

### **3.6.3 Confidentiality**

It was emphasised in the Patient Information Sheet that participation in the study was confidential. However, confidentiality was limited if there was an issue of risk to the patient or others and it was made clear to potential participants that clinical staff had to be informed in such circumstances. The limits to confidentiality and the audio recording of interviews were detailed in the information sheet and discussed with participants verbally before each interview. Written consent for the audio-recording of interviews was obtained from participants before the start of each interview. Participants were issued with study numbers in place of personal identifiers for the purpose of data collection, analysis and write-up.

### **3.6.4 Data storage**

Audio recordings, transcripts and consent forms were stored in a locked filing cabinet in NHS property only accessible by the researcher for the duration of the study. Electronic information for the purpose of data analysis by the researcher was stored on a NHS password protected computer and NHS password protected memory stick. Due to the intention of the researcher to publish the findings of the current thesis, all anonymised data (transcripts and hardcopies of data analysis) will be retained in a locked cabinet at the eating disorders unit for a period of 5 years. Identifiable data such as audio recordings have been erased.

### **3.6.5 Emotional impact on researcher**

Although the researcher had experience of conducting sensitive interviews as part of their clinical practice, she sought supervision from an identified clinical supervisor with eating disorder clinical experience throughout the study. This allowed the researcher to discuss concerns from the study and to encourage reflection upon feelings in relation to the content of participants' accounts.

## **3.7 Participants**

### **3.7.1 Method of sampling**

Qualitative methodology often uses purposeful sampling to examine the experience of a specific social group. The aim of the current study was to examine the inpatient treatment experiences of adult female patients with AN. It is recognised that qualitative differences may underlie different eating disorder diagnostic subtypes and thus the sample was limited to those with AN. Similarly, the research focussed upon female patients as research and clinical practice suggests that there is a greater prevalence of females being treated for AN (Fairburn & Harrison, 2003). The decision not to include male participants was made due to the unlikelihood of being able to recruit sufficient numbers to make meaningful comparisons between the experiences of males and females with AN and to keep the sample as homogenous as possible. There is little research on males with eating disorders, however clinical practice suggests that AN may manifest differently in males than in females and lead to different experiences.

### **3.7.2 Inclusion criteria**

Participants had to be female adult inpatients, aged 18-65, who met Diagnostic Statistical Manual Fourth Edition (DSM-IV) criteria (American Psychiatric Association, 1994) for AN as confirmed by psychiatric assessment upon admission and who were receiving inpatient treatment at the eating disorders unit. They also had to provide consent to be interviewed.

### **3.7.3 Exclusion criteria**

Participants could not have a short-term admission to the eating disorders unit (less than 10 days); have a diagnosis of bulimia nervosa or an eating disorder not otherwise specified (EDNOS); suicidal; suffering from a co-morbid psychotic disorder; or their inclusion deemed inappropriate by responsible clinical staff due to their current mental/physical state.

The total number of patients in the eating disorders unit during the current study, the number of patients who were excluded and the total number of patients who participated are outlined in Figure 3.1.



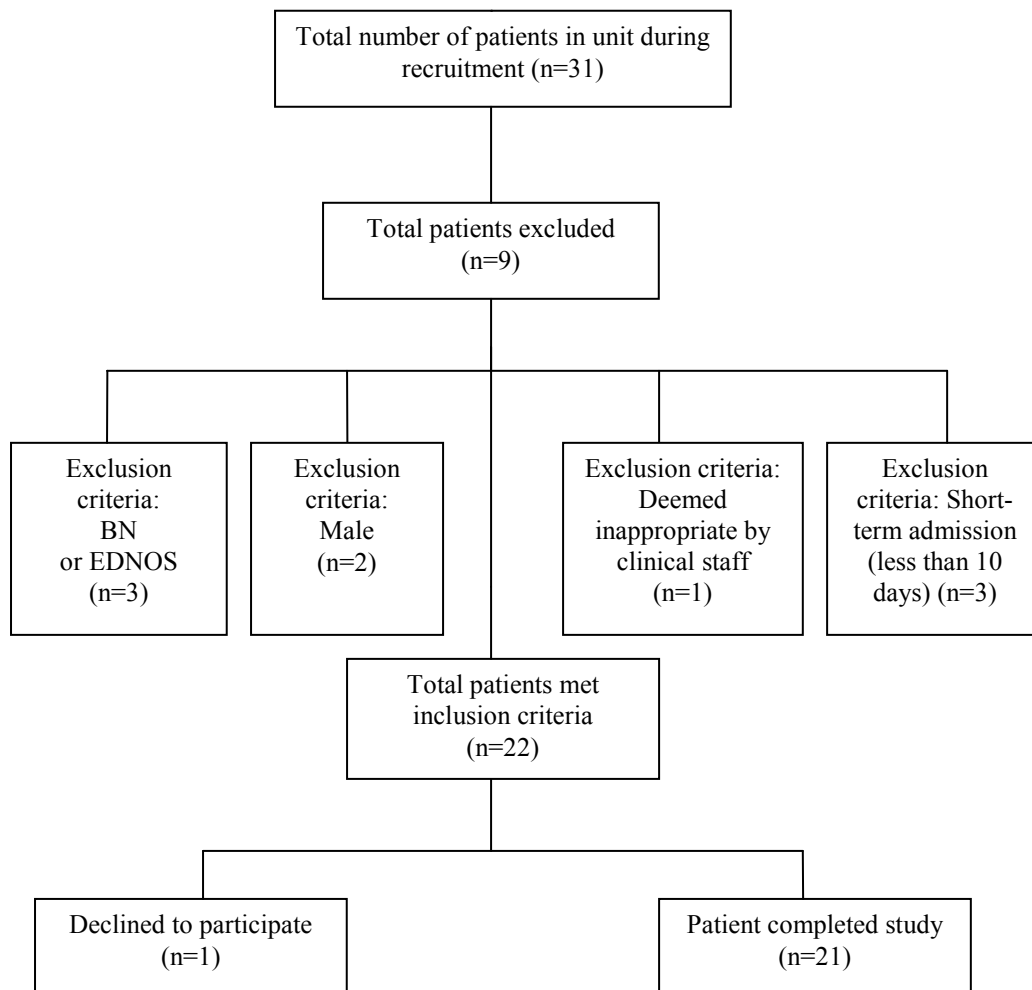


Figure 3.1 Flow chart showing number of patients identified, excluded and recruited.

### 3.7.4 Participant characteristics

Twenty-one female participants were interviewed in the current study. A summary of participant characteristics are presented in Table 3.1. Some characteristics are not provided on an individual basis to avoid the possible identification of participants. Ages of the participants ranged from 18 to 41 years ( $M = 25.2$  years;  $SD = 7.33$ ). At the time of interview, participants' Body Mass Indices (BMIs) ranged from 11.8 to 21 ( $M = 16.6$ ;  $SD = 2.79$ ). All but one participant had voluntary treatment admissions.

The length of time since initial diagnosis of AN has been given according to their own subjective reports during interview. It is recognised that the participants may have experienced eating disorder behaviours for different lengths of time prior to diagnosis.

Table 3.1 Summary of participant characteristics

<b>P</b>	<b>Age</b>	<b>Total perceived duration since initial diagnosis of AN (in months)</b>	<b>Number of prior admissions for AN to any inpatient facility</b>	<b>Length of current admission in eating disorders unit (in weeks)</b>
<b>1</b>	26	36	2	16
<b>2</b>	18	60	1	24
<b>3</b>	33	168	3	20
<b>4</b>	37	276	1	20
<b>5</b>	18	5	0	20
<b>6</b>	18	84	2	28
<b>7</b>	31	216	6	12
<b>8</b>	19	4	0	12
<b>9</b>	20	72	0	3
<b>10</b>	18	48	2	20
<b>11</b>	19	60	1	2
<b>12</b>	22	12	0	6
<b>13</b>	35	48	2	6
<b>14</b>	21	120	0	12
<b>15</b>	21	7	0	16
<b>16</b>	25	6	1	4
<b>17</b>	24	36	1	6
<b>18</b>	29	36	1	5
<b>19</b>	35	4	0	7
<b>20</b>	20	24	1	28
<b>21</b>	41	276	0	2

### **3.7.5 Sample size**

Phenomenological research is recommended to include a range of 6 to 50 descriptions to achieve a maximum variation of personal experiences (Morse, 1994; Sandelowski, 1995; Smith & Osborn, 2008). The sample size needed for qualitative research is dependent upon the nature of the aim, the level of homogeneity of the sample and the allocated time for analysis and reporting. Smith *et al* (2009) controversially suggest that numbers of 4-10 interviews for professional doctorates may be adopted, however it is recognised that larger samples may provide more detailed, multifaceted and reliable accounts of the experience under investigation. The current study aimed to recruit 20 participants allowing for an in-depth exploration of emerging themes yet still manageable within the time constraints of the study. An additional participant was interviewed towards the end of the current study (total participants = 21) as one of the prior interviews (P20) was considerably shorter in length (15.2 minutes) and less detailed than the other interviews.

### **3.7.6 Research context**

It is recommended in qualitative research that information regarding the context in which the study is conducted should be provided to limit potential biases. In this study the research context will be discussed in terms of the background of the researcher and the eating disorder inpatient unit.

The researcher had worked as a Trainee Clinical Psychologist within an NHS specialist eating disorders outpatient service for four years. The researcher had clinical

experience working with patients with a range of severe and enduring eating disorders, who had prior inpatient treatment.

The specialist inpatient eating disorder unit is situated within the independent sector. The service has established referral pathways with independent healthcare organisations and NHS health boards across Scotland, providing inpatient treatment for adults with severe and enduring eating disorders. The inpatient treatment programme promotes a multidisciplinary treatment approach providing a combination of group therapies, individual counselling and dietetic management, which are personalised to individual support needs. The treatment programme incorporates a range of interventions, which are primarily cognitive behavioural in theoretical approach and focus on emotional regulation skills and the enhancement of self-esteem. These include anxiety management, behavioural activation, social skills training and body image work. Dietetic aspects of the programme include meal supervision, nutritional education and meal preparation work.

### **3.7.7 Recruitment**

The recruitment procedure was devised in collaboration with staff at the eating disorder unit and followed specific stages to minimise patient distress. The researcher met with clinical staff to discuss the study and then briefly presented the study to a patient community meeting, which all patients attend as part of their treatment programme. Participant Information Sheets were distributed to the patient group, which detailed the background to the study and contact information for the Clinical Liaison for the study if patients had concerns or questions (see Appendix 3). Interview

booking slots were made available at the nurses' station with a choice of interview slots for interested patients to sign up. Patients were able to request whether they wanted the interviews to be conducted within a therapy room or their own room to make them feel more comfortable during the interview.

### **3.8 Procedure**

#### **3.8.1 Pilot interview**

The researcher sought advice from a clinical supervisor with experience in research with eating disorders and two academic supervisors with experience in qualitative health research when devising the interview schedule (see Appendix 6). They suggested minor changes to the original wording of the interview to reduce the potential for the inadvertent use of leading questions. They also suggested reducing the number of questions to prevent participant fatigue, given the likelihood of this due to the low weight of participants. The interview schedule was also reviewed and approved by the local area NHS Medical Research Ethics Committee. A pilot interview was carried out and the participant provided feedback on the interview process. An audio recording of the pilot interview was also reviewed by the clinical supervisor. The pilot participant and the clinical supervisor indicated that the interview schedule was appropriate and no further amendments were required. The pilot participant was included in the overall sample (N=21) and the pilot interview data was included within the results of the study.

### **3.8.2 Interview format**

Semi structured interviews were conducted to allow the researcher to ask specific questions while maintaining flexibility in following up responses. The interviews were conducted in two phases over a period of twelve months. The first phase (13 interviews) was carried out between January 2009-April 2009 and the second phase (8 interviews) was carried out between August 2009-January 2010. This was in part due to a low number of admissions to the unit at specific time-points during data collection and the researcher's maternity leave. No changes were made to the treatment regime during this time.

The length of the interviews ranged between 15 and 60 minutes, with a mean duration of 36.9 minutes (SD = 11.9). Interviews were conducted on an individual basis, within a clinical therapy room at the request of participants. Participants were reminded of the limits to confidentiality prior to the commencement of the interview and that in all other respects the information provided would be made anonymous.

The interview schedule was used flexibly throughout the interview to allow the exploration of issues that were raised by participants (see Appendix 6). The construction of the interview schedule followed recommendations from the qualitative literature (Smith *et al.*, 2009; Willig, 2001). Questions generally followed a chronological format and prompts were omitted or included depending on the participant's account. All interviews began with questions relating to participant characteristics (e.g. age, information on the length of time of diagnosis, length of current inpatient stay and number of previous inpatient admissions for AN) and ended

with questions relating to the experience of the interview. The researcher felt that it was not appropriate to ask information regarding current Body Mass Index (BMI) and type of admission (voluntary or compulsory order) at the time of interview due to the sensitivity of this information. Patient consent (in Participant Consent Form) was obtained to gather this data from patient clinical notes.

Questions were neutral and open-ended to avoid leading participants in a particular direction. Topic areas discussed within the interview were based on relevant literature (Colton & Pistrang, 2004; Offord *et al.*, 2006; Tierney, 2008). Each participant was initially asked “Can you tell me about your experiences of your eating difficulties?” This question was used to orientate participants to the research area and to their personal experiences of having AN. This allowed for further questioning in relation to their current perceptions of their condition and where they saw themselves in the recovery process. Each participant was also asked the second question of “Can you tell me about your experiences of this inpatient treatment programme for your eating difficulties?” This question was used to explore participants’ lived experiences of being an inpatient within the treatment programme. The researcher used further questioning to explore key factors of the experience including helpful/unhelpful aspects of treatment, living with other patients with eating disorders and suggestions for improving patient care. It is recognised that some participants may have also reflected on their treatment experiences of previous inpatient admissions to this unit or other hospital settings. The researcher tried to direct participants to describe their current treatment admission, while allowing participants some flexibility to compare their current experiences to previous treatment admissions.

Questions were followed up with non-directive prompts or short periods of silence to encourage further information and to clarify answers. Further prompts used in this study included asking for more information (e.g. Can you tell me more?), clarification of a specific example or experience (e.g. What would be an example of that?) or asking about thoughts or feelings in relation to an experience (e.g. How do you feel about that?).

The researcher frequently summarised information to check its accuracy and to ensure that participants felt that they had been heard. Participants were given an opportunity to provide further additional information at the end of the interview and asked about their experience of the interview.

While conducting the interviews, the researcher had to consider a number of issues, including organising interview times around mealtimes and monitoring potential fatigue levels of participants due to their low weight. The researcher was sensitive to the need to prevent disruption to meal routines or to conduct the interviews straight after mealtimes when participants may feel more vulnerable. The researcher was aware of physical consequences of AN such as fatigue and reduced cognitive functioning and monitored this throughout the interview, providing breaks as appropriate.

### **3.9 Data management**

Interviews were recorded using a digital voice recorder. After the interviews, recordings were stored as audio files on a NHS password protected computer and



erased from the digital recorder. Interviews were then transcribed verbatim using transcription equipment. A numerical code was assigned to each transcript and all personal identifiable information removed.

The researcher used a computerised qualitative data analysis package i.e. NVivo 8 (QSR, 2008) to store, organise and refine the data. The researcher coded the transcripts by hand and then entered these into the data analysis software.

### 3.10 Data analysis

There are a number of variations in the analytical process of IPA. In general, emphasis is placed upon the process of moving from individual accounts to shared themes with the aim of exploring the assigned personal meaning of the experience. The data was analysed using a step by step guide to conducting IPA analysis that is recommended for use by inexperienced qualitative researchers (Smith *et al.*, 2009). These steps are summarised in Table 3.2.

Table 3.2 Summary of step-wise analysis of IPA (Smith *et al.*, 2009)

Step	Analysis
1	Reading and re-reading
2	Initial noting
3	Developing emergent themes
4	Connections across emergent themes
5	Moving to the next case
6	Looking for patterns across cases

**Step 1: Reading and re-reading:**

Audio recordings of the interviews were transcribed and the researcher became actively engaged with the data through repeated reading of individual transcripts. Comments, thoughts and reflections were noted in the researcher's reflective diary to aid later interpretation.

**Step 2: Initial noting:**

The researcher used exploratory coding to initially analyse each transcript. This included the use of "descriptive" comments to describe the content of the account, "linguistic" comments to describe the use of language within the account and "conceptual" comments to provide an interpretation of the account. Comments were made on a line by line basis and documented in the right hand margin of the transcript (See Appendix 7).

**Step 3: Developing emergent themes**

The researcher identified themes through the exploration of patterns of description within the initial notes. The themes represent an attempt to capture important reflections within the account, reflecting both the participant's and the researcher's interpretation of the experience (Smith *et al.*, 2009). According to Smith and Osborn (2008), themes consist of phrases that move the researcher's initial notes of the text to a more abstract and conceptual level. Smith and Osborn (2008) also comment that theme titles often relate to psychological or cognitive constructs to allow for a greater conceptual understanding of the participant's experience and sense-making of the

phenomenon. Emerging themes were documented in the left hand margin of the transcript (see Appendix 7).

**Step 4: Connections across emergent themes:**

The researcher explored connections between emergent themes to produce a higher level, super-ordinate theme to describe or label a cluster of similar themes. This stage was facilitated using a qualitative data analysis package, which allowed the researcher to organise themes and super-ordinate themes. A summary table of emergent themes and the development of super-ordinate themes was then produced. An example of a table of themes generated for participants can be seen in Appendix 8.

**Step 5: Moving to the next case:**

In line with the idiographic principles underlying IPA, the researcher repeated steps 1 to 4 for each participant's account, allowing for the identification of new themes from each account.

**Step 6: Looking for patterns across cases:**

The researcher compared summary tables for each participant to identify both shared super-ordinate themes across the group and instances of isolated themes that were not consistent throughout the group. The researcher also went back to earlier transcripts to identify examples of themes which were only originally identified in later transcripts.

Super-ordinate themes were considered recurrent if they recurred in at least a third or more of the sample (Smith *et al.*, 2009). Summary tables of super-ordinate themes

were manually integrated into a table of master themes and sub-ordinate themes for the group. The master themes and sub-ordinate themes were then checked with each participant. Summary tables of the distribution of recurring super-ordinate themes, master themes and sub-ordinate themes for all participants can be seen in Appendix 9. For an example of extracts relating to the master theme, “sharing with peers” see Appendix 10.

### **3.11 Demonstrating quality**

#### **3.11.1 Introduction**

In quantitative research the value and methodological rigour of a study is evaluated against criteria of reliability, validity and generalisability. Criteria for establishing methodological quality and rigour within qualitative research have been criticised for the variability in terminology and the reliance upon overly prescriptive technical procedures (Barbour, 2001; Meyrick, 2006). The researcher followed published core flexible principles for establishing quality within qualitative research; sensitivity to context, commitment and rigour, coherence and transparency and impact and importance (Yardley, 2000, 2008). These principles and the steps undertaken by the researcher are described in detail below:

#### **3.11.2 Sensitivity to context**

The value of qualitative research must be demonstrated through its sensitivity to the theoretical and socio-cultural context. Smith *et al* (2009) suggest that in IPA, the relevant literature is used to direct the study to demonstrate sensitivity to context. The researcher was sensitive to the existing qualitative literature concerning adolescents’

views of inpatient treatment for eating disorders, adults' perspectives of recovery and treatment satisfaction.

Using IPA in the current study also demonstrates sensitivity to context as a thorough data collection process requires an in depth awareness of the interview process including the demonstration of empathy and an awareness of possible power differences between the researcher and the participant (Smith *et al.*, 2009). The researcher was sensitive to the possible impact that her role as a Trainee Clinical Psychologist could have on participants, particularly in regard to eliciting views on current practices within the eating disorder unit. The researcher was aware that participants may associate her role with that of staff in the unit and therefore be reluctant to discuss views that may lead them to be seen in a negative way. However, the researcher was not involved with the past, current or future care of the participants who took part in the study. Participants were informed that the researcher worked clinically in an outpatient eating disorders service within another health board and was independent from the eating disorder unit. They were informed that their participation in the current study would not affect their current or future care. They were also informed that all transcripts would be anonymised.

### **3.11.3 Commitment and rigour**

The second principle of rigour and commitment in qualitative research refers to the provision of a sufficient level of detailed analysis to ensure the validity of results. Commitment can be demonstrated in several ways via extensive engagement with the topic, methodology and participants' accounts. As part of conducting in-depth IPA

interviews, the researcher demonstrated commitment through her level of attentiveness and sensitivity to the care and reports of participants' during the interview process (Smith *et al.*, 2009). The researcher also transcribed all the interviews and replayed the interviews while reading the transcripts to develop an in-depth engagement with the data. The application of the step-wise framework of analysis in IPA also demonstrated the level of description and care given to the analysis.

The researcher utilised a range of methods to strengthen the rigour of the study including sampling, triangulation and respondent validation checks. The researcher interviewed patients specifically with a diagnosis of AN to keep the sample relatively homogenous, while including those at different treatment stages to purposively sample a broad range of possible perspectives. As Smith *et al* (2009) propose, the application of IPA advocates a clear system of analysis demonstrating idiographic engagement and further interpretation of the description beyond the individual level. The researcher repeatedly checked the themes against each individual transcript to ensure that the themes were developed from the data. The researcher also demonstrated the detailed and systematic process of analysis in the current study through the use of supportive quotations from participant accounts and the use of summary tables to illustrate patterns of themes.

Triangulation (seeking information from multiples sources or methods) was used to compare and refine interpretation of participant accounts. Barbour (2001) argues against using different methods to collect data and instead suggests that qualitative interpretations should be compared against each other to enrich the findings. Samples

of coded transcripts (n=5) were reviewed by a clinical supervisor who had experience in working with patients with eating disorders and an academic supervisor with experience in qualitative research. This provided the corroboration of identified themes and the refining of themes in light of differing perspectives. In addition, the researcher was part of a research group held between the eating disorders outpatient service and the local area NHS psychological therapies service. The researcher was also part of a small qualitative supervision group, run by an academic staff member with experience in qualitative research and attended by Trainee Clinical Psychologists who were undertaking qualitative research. The researcher distributed random coded samples within both of these research groups for discussion, which helped to further refine interpretations of the transcripts and gain different perspectives on the coding.

The researcher recognised the importance of respondent validation to assess whether the findings accurately represented participants' views. As all of the participants were discharged from the eating disorders unit during the research process, the researcher held a small focus group with four female inpatients who were currently receiving treatment within the unit to review the identified themes. These patients did not participate in the interview process, but were aged between 18 and 65 years ( $M = 28.8$ ;  $SD = 7.36$ ) with AN, reflecting similar characteristics to those interviewed. The length of their current treatment admission in the unit ranged from 6 to 28 weeks ( $M = 15.5$ ;  $SD = 9.29$ ).

The researcher also sent summaries of the preliminary findings to the participants who had taken part in the interviews (permission was sought at interview), providing

opportunity for feedback (see Appendix 11). No feedback was received from participants after they were sent the summary of the findings.

#### **3.11.4 Coherence and transparency**

The third principle refers to coherence and transparency. Coherence refers to the presentation of findings that are consistent with the theoretical background and applied methodology of the study. The researcher's clinical and academic supervisors reviewed samples of the transcripts and drafts of the write-up of the current study to check that these were in keeping with the aims of the current research, the theoretical background and the underlying principles of IPA. The researcher also presented the integration and relationship of themes in a pictorial diagram.

Transparency refers to the clear documentation of all aspects of the research process in order to assess the extent to which the findings would be repeated if the study were to be replicated in the future. The researcher provided a clear description of the sampling, interview schedule and the elements of analysis in the current study. The researcher used a qualitative data analysis package to organise and refine the development of codes. The researcher also presented examples of quotations and summarised themes to provide further evidence of the analysis.

Reflexivity is considered to be an important aspect of transparency where the researcher details their position within the research process. Consideration of the role of the researcher is important within IPA as the researcher is required to provide an interpretation of participant accounts. The researcher utilised a reflective diary



throughout the study to maintain a reflexive stance. This included detailing and evaluating prior assumptions and knowledge from clinical experience, the potential influence of the researcher's and her supervisors' influences on the research process and the interpretation of the data.

### **3.11.5 Impact and importance**

The final principle is concerned with the impact and importance of the research. This refers to the contribution of the current research findings to theoretical knowledge or practice within the research area. Reference to this principle is included within several quality appraisal checklists of qualitative research (e.g. CASP, 2004; Mays and Pope, 2000; Popay, Rodgers & Williams, 1998). Tierney (2008) argues that examining patient views regarding inpatient care for AN is an important process in the development of more effective services.

## 4. RESULTS

### 4.1 Introduction

The aim of the current study was to describe the treatment experiences of adult female inpatients with anorexia nervosa. Participants' accounts highlighted positive and negative experiences of their current inpatient treatment admission.

The analysis produced an initial eleven super-ordinate themes from the participants' interviews. There were differences in the presence of the super-ordinate themes within individual interviews however these themes recurred in at least a third of the overall sample. The researcher reviewed the eleven initial super-ordinate themes against each transcript to compare with how the participants reflected on their experiences (see Appendix 9). The initial super-ordinate themes were re-grouped into five master themes which the researcher felt reflected the shared experiences of the sample: *Shifts in control; Experience of transition; The importance of supportive staff relationships; Sharing with peers and Process of recovery and self-discovery.*

Participants 1, 2, 3, 4, 6, 11, 14 and 15 provided rich and detailed descriptions of their treatment experiences, covering a greater number of sub-ordinate themes. With the exception of participant 11 who had been in the unit for 2 weeks, these participants had all been receiving their current treatment for approximately 4 to 7 months and the greater detail of these interviews may reflect their increased time to experience aspects of treatment. Participants 7, 8, 9, 10, 16, 20 and 21 provided less detailed descriptions in their narratives, covering fewer sub-ordinates themes overall. Five of these participants had been receiving their current treatment for three or less months, giving

them less time to reflect on their treatment experiences. A summary of the master themes and related sub-ordinate themes can be seen in Table 4.1

**Table 4.1 Overview of master themes and sub-ordinate themes**

<b>Master Themes</b>	<b>Sub-ordinate themes</b>
<i>1. Shifts in control</i>	1.1 Handing over of control of eating behaviours 1.2 Living within the restrictive environment 1.3 Regaining control 1.4 Seeking greater collaboration in treatment
<i>2. Experience of transition</i>	2.1 At the start I didn't want to be here 2.2 Treatment as a safe environment 2.3 Loss of normality: inside the safety bubble 2.4 Back to reality: concerns about loss of support and fear of relapse
<i>3. The importance of supportive staff relationships</i>	3.1 Importance of trust and making connections 3.2 Importance of being seen as a whole person not a walking eating disorder 3.3 Perceived inconsistencies in staff support
<i>4. Sharing with peers</i>	4.1 I am not alone – benefits of peer support 4.2 Learning from peers 4.3 Envy of emaciated peers 4.4 Coping with others' distress
<i>5. Process of recovery and self discovery</i>	5.1 Recovery as an arduous process: contrast between physical restoration and AN recovery 5.2 Role of self-motivation 5.3 Self-discovery and regaining confidence

A detailed description of each master theme and its sub-ordinate themes (indicated using italics) will be presented with reference to direct quotes from participant transcripts. The extracts were selected because they provide the most coherent expression of the themes, while representing the views of the sample. All names have been removed to protect anonymity with the source of each quotation indicated by the participant's assigned research number and the duration of their inpatient treatment (in weeks) at interview.

The chapter concludes with a summary of the relationships between the master themes reflecting the sense-making of the experience of the inpatient treatment programme for the participants.

## **4.2 Overview of themes**

### **4.2.1 Shifts in control**

The first master theme, “shifts in control”, describes participants’ experiences of changes in their perceived levels of personal control throughout their treatment. The changes in participants’ perceived levels of control did not follow a linear process and the majority of accounts were characterised by conflicting emotional reactions. This master theme is comprised of four sub-ordinate themes: (1) handing over of control of eating behaviours; (2) living with the restrictive environment; (3) process of regaining control; and (4) the seeking of collaboration in treatment.

#### ***4.2.1.1 Handing over of control of eating behaviours***

Several participants talked about their tiring preoccupation with their eating behaviours prior to treatment, highlighting a gradual deterioration of personal control over their eating disorder. Participants described feeling a sense of being controlled by their eating disorder. Participants discussed how the handing over of all personal control within treatment was necessary for recovery. The handing over of perceived control in treatment appeared to provide relief from the responsibility of decision making and ritualised daily routines of eating and exercising. For some, entering into inpatient treatment allowed an escape from the control possessed by their eating

disorder, which had seemed impossible to achieve in their home environment. Thus, the transfer of personal control in treatment to staff may be seen as an interim step towards attempts to regain control from their eating disorder.

*“...we get all meals in here and there is no option to have them or not, you must have them. The decision has been taken away from you almost and definitely if I hadn’t been an inpatient I wouldn’t have been able to eat” (Participant 5, interviewed at 20 weeks).*

*“Your food starts to become your life and you are focussing on that rather than you controlling your life, food controls that...Before I came here I couldn’t see any way of me getting better because I knew it was my power and I couldn’t do it” (Participant 11, interviewed at 2 weeks).*

*“...you don’t have to think about, you don’t have to control it anymore and you can give over that control...it just feels as if you are in that stage where you can’t make any decisions and you are completely in a rut so it is nice to have other people take over” (Participant 17, interviewed at 6 weeks).*

In contrast, a few participants talked of feeling anxious at handing over the level of personal control that their eating disorder provided. They felt that their eating disorder provided a sense of familiarity and a level of perceived control over their emotions and behaviour. Without the control provided by their eating behaviours, some participants felt exposed and vulnerable. An exemplar of this is provided by Participant 3, who reflects retrospectively on her feelings at handing over control during admission:

*“...an eating disorder gives you a level of control and I was in control of me... agreeing to come into inpatient treatment means you are definitely handing over all control...it was very, very scary thinking if I come into treatment I have to hand over all control the eating disorder gave me. That made me feel very unsafe...” (Participant 3, interviewed at 20 weeks).*

This experience was common to those recently admitted:

*“I have no control over any of the food and I do not have any control over anything...It raises my anxiety to the point I suffer very bad panic attacks” (Participant 9, interviewed at 3 weeks).*

Participant 9 was interviewed early into her inpatient treatment admission, reflecting the dominance of a perceived loss of control and associated psychological distress as she struggled to adjust to her hospital environment. Her perception of a loss of control is not limited to her eating behaviours, but also links to her overall sense of self-control.

#### **4.2.1.2 Living within the restrictive environment**

Most accounts were characterised by conflicting views of the structured treatment environment. Participants described their dislike of the structure and restrictions placed on them within treatment. They felt the restrictive environment led to feelings of disempowerment and made it difficult to engage with behaviours that provided a sense of control. However, participants also acknowledged that the restrictive environment was necessary to facilitate recovery as it removed opportunities to engage in their eating disorder behaviours.

*“...it is very restrictive and you hate that at first at how restrictive it is. There are no walks at first and your movement is limited and you are watched constantly but it is needed...” (Participant 1, interviewed at 16 weeks).*

*“when you first come in you have a lot of restrictions on you which I think is much as people moan about them I think they are what is needed” (Participant 5, interviewed at 20 weeks).*

The provision of too much choice and lack of structure in a previous inpatient admission to another hospital had exacerbated the eating difficulties of one participant:

*“When I was staying in another hospital I got worse in there because I was given too much choice...Here it is more structured and it gives you a role to look forward to...sometimes getting your choice taken away is better. It’s all about control and we don’t have it and it shows you it is not all bad” (Participant 16, interviewed at 4 weeks).*

The structured environment of her current treatment admission provided her with a sense of routine and the removal of choice enabled her to challenge her eating difficulties and fears of losing control.

#### **4.2.1.3 Regaining control**

Some participants described the process of gradually regaining a “normal” level of control over their eating and life during treatment. Initially, participants questioned their ability to cope with decision making without their eating behaviours. The researcher interpreted that these feelings of uncertainty arose from low self-confidence and their previous over reliance on their eating disorder to achieve control. A sense of empowerment over time was emphasised within the narratives in relation to feelings of being liberated from the control that their eating disorder previously had over them and achieving the ability to make personal choices about their life that were not governed by their eating behaviours.

*“...you think can I cope, can I manage but then as you actually do manage and cope without using eating disorder behaviours it is so empowering and you think I can actually do this, I can take control, I can take a normalised control over my well-being and it is me in charge here...” (Participant 3, interviewed at 20 weeks).*

A few participants provided examples of the gradual reduction of restrictions as they progressed during treatment. As a result, they felt a sense of growing freedom in treatment.

*“You are allocated one 15 minute walk...and then it goes up to two 15 minute walks with staff. It moves onto walks with other patients so you are out unsupervised...you are gaining that little bit more control back...” (Participant 3, interviewed at 20 weeks).*

*“..when you first come in there are a lot restrictions put on you, you are not allowed to leave the wards... then as you progress through treatment these things are slowly lifted off” (Participant 6, interviewed at 28 weeks).*

In contrast, one participant spoke of the lengthy process of having her level of restrictions reduced in treatment. Her account portrayed feelings of frustration at not being able to progress as rapidly as she wanted.

*“Sometimes it can be quite a long process to get up to it because you need to go through all the stages and it can be quite...you want to do something and you can’t because you have got to (silence)...” (Participant 5, interviewed at 20 weeks)*

#### **4.2.1.4 Seeking greater collaboration in treatment**

Some participants spoke of their wish to become more involved in their treatment. Opportunities for feedback were perceived to be limited to the evaluation of treatment modalities. Some participants described having limited opportunities to attend review meetings or having decisions made about their care by staff who they had limited contact with. This left some participants experiencing a power imbalance between themselves and senior staff members and confusion at the lack of feedback in relation



to changes to treatment plans. Feeling uninvolved in treatment planning led to feelings of anxiety and a reduced sense of perceived control.

*“They make every decision even although they see you 10 minutes a week and they have overall power” (Participant 2, interviewed at 24 weeks).*

*“...sometimes I feel I am out of the loop and everyone knows what is going on and I find that it makes me feel really anxious because this is me and I am in the middle of it all and everyone is deciding what is happening and nobody is asking me” (Participant 18, interviewed at 5 weeks).*

Participants highlighted their desire for greater involvement in treatment discussing possibilities for increased discussion of their care with staff and attendance at ward meetings.

*“Just for the patient’s opinions to get considered more...Personally I would like to go into ward rounds to hear what is said” (Participant 4, interviewed at 20 weeks).*

*“..I feel if they discussed more with you, where do you think you are, how can we approach this....” (Participant 12, interviewed at 6 weeks).*

There was a shared consensus that having time to discuss their treatment plans would facilitate patient understanding and improve acceptance of treatment recommendations. Specifically, the importance of collaboration in treatment was highlighted by participant 13 who was on her third admission. She described how she had previously left treatment from another inpatient unit due to her frustration at feeling her views were ignored by clinicians.

*“I left because I did not feel I was being listened to and I did not feel my views were being listened to or heard” (Participant 13, interviewed at 6 weeks).*

This contrasts with her current inpatient experience where she had developed a shared working agreement with unit staff prior to admission, which described her views about her support needs. This provided her with a greater sense of perceived control within treatment and enabled greater treatment acceptance.

*“...the whole care plan was decided before I came in...when I have been close to leaving that has been what has kept me here...so making a clear working agreement which I had has certainly been helpful...things spelt out clearly helps dispel worry...” (Participant 13, interviewed at 6 weeks).*

#### **4.2.2 Experience of transition**

The second master theme, “experience of transition”, represents the process of transition between the home and treatment environment. This master theme is comprised of four sub-ordinate themes: (1) at the start I didn’t want to be here; (2) treatment as a safe environment; (3) loss of normality: inside the safety bubble; and (4) back to reality: concerns of loss of support and fear of relapse.

##### **4.2.2.1 At the start I didn’t want to be here**

Some participants described their initial experiences and reactions to their transition from their home-life into inpatient treatment. They spoke about their early difficulties in trying to adjust to the structured treatment environment and their separation from family and friends. The initial weeks of treatment was a time of intense emotional

distress and confusion for participants, even for those who had prior experiences of inpatient treatment.

*“When I first came in, my first three weeks, I can vaguely remember them and I was so angry at being in there again and so ashamed, disappointed” (Participant 1, interviewed at 16 weeks).*

*“...at the start I didn’t want to be here...I was scared because I hadn’t been away from home...I was really nervous about it and at the start I hated it and wanted to get home” (Participant 2, interviewed at 24 weeks).*

*“I had gone from a home, stress-free not having to deal with anything in life... Then I came in here...Oh my goodness, I had a headache for the whole first week or 10 days or something because it was so much...” (Participant 11, interviewed at 2 weeks).*

Linked to the previous theme, “seeking greater collaboration in treatment”, a few participants spoke about feelings of confusion in relation to their lack of information about what to expect from inpatient treatment. The differences between their treatment expectations and their actual experiences of the structured treatment environment contributed to their initial difficulties in adjusting to the treatment environment.

*“I know from my first admission that I didn’t think I was going to have to eat...a lot of the patients do not realise what is expected of them” (Participant 1, interviewed at 16 weeks).*

*“...maybe more should be explained when you come in...you do not know what is happening and at that time you are confused and worried...” (Participant 2, interviewed at 24 weeks).*

*“Sometimes you hear something but you are not clued on the information...there is so much confusion if you are not informed about things” (Participant 11, interviewed at 2 weeks).*

#### **4.2.2.2 Treatment as a safe environment**

Most participants spoke about their growing sense of attachment to the treatment environment over time. Many spoke about feeling “safe” in the treatment environment, as it offered protection from everyday life stressors. The structure of the treatment environment also provided a sense of familiarity and routine for participants. Inpatient treatment was perceived as life-saving and necessary for recovery due to the provision of intensive support, which was rarely provided in outpatient services.

*“I know I definitely needed it and could not have done it as an outpatient to start with, there is just not the supervision required” (Participant 14, interviewed at 6 weeks).*

*“...it comes to a time when you call this home. You are quite settled and safe in here” (Participant 19, interviewed at 7 weeks).*

*“...it has basically saved my life...Overall it has been a good experience” (Participant 20, interviewed at 28 weeks).*

A few participants acknowledged that their growing dependency on the treatment programme had led to feelings of unease at the prospect of being discharged home. Participant 6 talked of her attachment to the treatment environment and her fear of returning home:

*“...the more you get used to things you start feeling comfortable and you become dependent on it... you feel it is your safe place almost. I kind of feel I am almost afraid to be here now because I have become quite attached to it and quite dependent on it” (Participant 6, interviewed at 28 weeks).*

#### **4.2.2.3 Loss of normality: inside the safety bubble**

Most participants spoke about feeling removed from a sense of “normality” in the treatment environment. There was a degree of conflict in participants’ attitudes in relation to the impact that this had on their treatment and recovery. Some participants felt that the removal from their home environment and everyday stressors was necessary to allow them to solely focus on their recovery.

*“I think it is helpful being away from your environment...your house is where all the things happened, where you got ill so I think it would be harder to get better in that environment...” (Participant 5, interviewed at 20 weeks).*

*“I would rather spend a bit more of that time here...you can forget about everything and focus on getting better because there are no distractions and it is like your life at home is on hold” (Participant 17, interviewed at 6 weeks).*

However for other participants, the treatment environment was too protective and prevented them from achieving recovery in a “normal” environment. As treatment progressed there was a growing perception of the differences between the treatment environment and their home environment. These participants spoke of their dislike at the loss of normality in treatment and felt worried about how they would maintain their recovery following discharge when faced with additional everyday life stressors and eating in social environments.

*“...it can be a bit unreal in here as well because it is a bit of a safety bubble... You notice when you go out on pass it is so much easier in here.... you do not have to eat your meals and no one is going to sit and make you eat” (Participant 4, interviewed at 20 weeks).*

*“...you can feel a bit institutionalised...it is hard to imagine the real world of going to work, earning money, dealing with the pressures of life...it becomes a bit scary when you have to think about going back into the real world” (Participant 6, interviewed at 28 weeks).*

*“It is too much of a safe house...The normality side of living in here I do not like because it is farther from normality than you could imagine, its like Big Brother...” (Participant 15, interviewed at 16 weeks).*

Participants expressed a desire to re-connect with “outside life” in treatment through the request of external social activities and the ability to practise behavioural skills outside the inpatient unit.

*“...I do not enjoy going down to the table eating with people who are struggling so much, I like to do it in a more normal environment and I am trying to go out more with my family...I need more normality in treatment” (Participant 15, interviewed at 16 weeks).*

*“...maybe more time out of the ward...sometimes you can feel like you are trapped there and it isn't any world other than here” (Participant 6, interviewed at 28 weeks).*

*“...they took us to the pictures...a normal thing to do and it was nice to know there is life outside whereas when you're in there 24/7 you can feel a bit like oh, you know” (Participant 18, interviewed at 5 weeks).*

The ability to carry out normal activities within the treatment programmes provided the participants with a sense of relief from feeling institutionalised within the treatment environment.

#### **4.2.2.4 Back to reality: concerns of loss of support and fear of relapse**

Some participants were aware of the initial difficulties in accessing specialist treatment and feared a lack of availability of outpatient support following discharge from the inpatient treatment programme.

*“There should be more facilities and even outpatient for when you go out. I know that is starting to build up but I know there is nothing in my area feasible to go to” (Participant 2, interviewed at 24 weeks).*

Participant 1, who had experienced a previous admission to the eating disorders inpatient unit, described the lack of follow-up care following discharge:

*“...you go from being an inpatient in here to going out and maybe seeing someone once a week... last time I left here I didn't even have a G.P. and my consultant didn't contact me...there is very little support out there” (Participant 1, interviewed at 16 weeks).*

Linked to the previous theme, “loss of normality”, some participants also discussed their fears of being unable to maintain their recovery following the transition from the inpatient treatment environment. There was a growing sense of unease and uncertainty at their ability to maintain their treatment progress in their home environment.

*“...I find once they start introducing the food again I can carry on and get myself up to weight but it is soon as they have to step into the real world I do not know what to do and panic” (Participant 11, interviewed at 2 weeks).*

*“...I do worry about what it will be like when I go home and If I will be able to manage or maintain a minimum BMI” (Participant 13, interviewed at 6 weeks)*

*“...I think I would relapse if I did not have the support of all the nurses and staff” (Participant 14, interviewed at 12 weeks).*

### **4.2.3 The importance of supportive staff relationships**

This master theme has been divided into the following themes to reflect the experiences of staff support within the inpatient unit: (1) importance of trust and making connections; (2) importance of being seen as an individual; and (3) perceived inconsistencies in staff support.

#### **4.2.3.1 Importance of trust and making connections**

Participants discussed the process of building supportive and trusting relationships with both nursing staff and named therapists within the unit. Participants appeared to connect well with staff who adopted a firm and consistent but supportive approach.

*“...I know if someone is too nice I can wrangle them where as if someone is like that ‘No! This is how it is going to be’ I listened to that a little bit more, the tough love sort of thing” (Participant 1, interviewed at 16 weeks).*

*“I think they are so supportive and even if they do not know what to say, really just talking about the telly to you can take your mind off it and you know they are always there...” (Participant 2, interviewed at 24 weeks).*

Some participants spoke of marked difficulties in their ability to actively seek support in treatment at times of distress. The development of trusting relationships with staff facilitated help seeking behaviours, providing the confidence to disclose personal difficulties in treatment.

*“...you build up trust and you know you can say things to them and they understand a bit more because they know more about your past and where you have been...” (Participant 2, interviewed 24 weeks).*

*“It is good to know that you have almost a friend to talk to and someone who is a nurse and you feel you can have trust with then that*



*can be helpful. Sometimes it is easier to open up, how you are feeling, behaviours or if you are struggling” (Participant 6, interviewed 28 weeks).*

*“...I can trust them...it takes a relief off my mind so if I use any behaviours I will be able to tell them” (Participant 9, interviewed at 3 weeks).*

When participants did not perceive a connection with staff, feelings of distrust and seeking out of alternative means of support from other people during difficult times often resulted.

*“It feels as if I haven’t had an opportunity to develop a relationship with my key therapist at all... so it is really hard to seek out help and ask for help” (Participant 13, interviewed 6 weeks).*

*“...When there’s a day where they are staff...you cannot find a connection with, it is hard if you’re having a bad day and I would pick up the phone before going to them...”(Participant 15, interviewed at 16 weeks).*

#### **4.2.3.2 Importance of being seen as a whole person not a walking eating disorder**

Most participants discussed their expectations of individualised, person-centred care within treatment. They wanted to be acknowledged as individuals, highlighting the importance of a holistic treatment approach which addressed both the underlying physical and psychological issues associated with their eating disorder. Opportunities to engage in individual therapy sessions to address psychological issues were felt to be essential in treatment.

*“I think that one to ones we have with our therapists are very important because they help to tackle individuals problems rather than generally doing things. They really personalise it for you*

*which I think is necessary” (Participant 5, interviewed at 20 weeks).*

In contrast, participants felt that treatment which neglected their psychological wellbeing would lead to relapse.

*“...I think it is really important to look at what caused you to become ill because that needs to be resolved otherwise it will niggle at you and cause a relapse” (Participant 5, interviewed at 20 weeks).*

*“People might appear to be looking better...but inside they are not always and it is important not to just focus on the physical and eating aspect of it because it is really not the main problems...” (Participant, 11, interviewed at 2 weeks).*

One participant spoke about her frustration at the lack of recognition for her personal progress in treatment within areas which were not related to weight gain. This led to a sense of resignation and a reduction in her motivation to continue in treatment.

*“...I feel like I am making progress despite the fact my weight is not going up yet I feel like that has not been acknowledged... I guess I feel I am putting in a lot of effort and it all comes back to weight in the end...It is all about feeding you up” (Participant 18, interviewed at 5 weeks).*

Some participants spoke about valuing staff in the unit who adopted a person-centred approach, considering individual preferences within treatment for certain food and activities. Staff interactions which made participants feel “normal” and less like a “patient” were highlighted as important.

*“... they do not treat you as if you have a problem. They are quite good at keeping you as an individual and they do like to get to*

*know you and know you without your eating disorder...”(Participant 1, interviewed at 16 weeks).*

*“I felt as if have been seen more as a whole person rather than a walking eating disorder which I have felt in the past...”(Participant 13, interviewed at 6 weeks).*

The holistic, person-centred approach undertaken by most staff in the inpatient unit appeared to facilitate the development of trusting and supportive relationships in treatment, increasing participants’ acceptance of the treatment programme.

In contrast, a few participants spoke of staff members who they perceived as making assumptions about their behaviours due their eating disorder. They felt that some staff members were unable to consider the existence of individual food preferences or allergies that were separate from their eating disorder behaviours.

*“... you are just an eating disorder...when you say how you feel that is not you that is your eating disorder talking...”(Participant 6, interviewed at 28 weeks).*

*“...it is always assumed that every single thing we say is an eating disorder. That is not always the case. Yes sometimes it is but people genuinely do have likes and dislikes...sometimes the gauge doesn’t not seem to be there” (Participant 11, interviewed at 2 weeks).*

The perceived inability of some staff to recognise their individuality resulted in feelings of frustration.

#### **4.2.3.3 Perceived inconsistencies of staff support**

While some participants felt supported by staff on the unit, others were less positive. Some participants perceived inconsistencies in the level and availability of staff

support in the unit. They felt that inconsistencies in staff support led to a sense of unfairness and lack of support at times. There was also a suggestion that some patients were able to manipulate those with a less firm approach to their own benefit.

*“Sometimes there are inconsistencies...People would display behaviours some staff would pick up on it and stop them doing it and other staff wouldn’t. You know what you get off with depending on the staff member...” (Participant 11, interviewed at 2 weeks).*

*“Sometimes I feel I am not supported and sometimes I feel I’m getting loads of support...It depends who is on and how much staff is on so it varies” (Participant 14, interviewed at 12 weeks).*

Participants noted their dissatisfaction with their difficulties in accessing support from staff. While acknowledging the extent of staff responsibilities in the unit, participants at times felt overlooked, particularly in comparison to newly admitted patients. It seemed to them that their support needs were not considered as important.

*“...sometimes you are needing to speak to somebody and you can’t speak to them... they have to see the new admissions before they see anybody but I have issues as well...” (Participant 2, interviewed at 24 weeks).*

*“...you’re wanting to get a hold of someone to see someone and you can’t get hold of anyone. You will say can I speak to you when you have got a few minutes and you’ll see them go home and they’ll say I forgot to speak to you because I was too busy...” (Participant 12, interviewed at 6 weeks).*

Participants also felt that their progress in treatment was hampered by unhelpful staff attitudes and behaviour. Such perceptions increased feelings of frustration, anxiety and being misunderstood.

*“...sometimes they are crabbit with you... I feel like they treat you like you’re stupid just because you have an eating disorder....” (Participant 6, interviewed at 28 weeks).*

*“...sometimes they get something wrong and you try to confront them about it and they point blank tell you, you were wrong... Some of their attitudes can be quite annoying...” (Participant 7, interviewed at 12 weeks).*

*“...if you have someone you are not comfortable with or you know they are quite snappy with you then you become paranoid and if there is food and you are struggling and you are worried they’re going to shout at you that makes you struggle more” (Participant 12, interviewed at 6 weeks).*

#### **4.2.4 Sharing with peers**

This master theme has been divided into the following themes to reflect the experiences of living with other patients who were also receiving treatment for anorexia nervosa and other eating disorders: (1) I am not alone – benefits of peer support; (2) learning from peers; (3) envy of emaciated peers; and (4) coping with others’ distress.

##### **4.2.4.1 I am not alone – the benefits of peer support**

Participants spoke of the importance of peer relationships in treatment. On reflection to their life prior to admission, most participants spoke of their feelings of isolation and being misunderstood by their family and friends. In contrast, participants described feeling understood and accepted by their peers in treatment, making them feel as if they were “not alone” in their experiences of their eating disorder. They expressed a sense of relief at being able to talk about their feelings without being judged or misunderstood. Participants perceived a level of shared understanding by their peers that was above that found in their relationships with staff.

*“Being around peers is positive in the sense that you get a lot of peer support and you are with people who are experiencing the same thing as you, it makes you feel you are not alone with the illness...” (Participant 3, interviewed at 20 weeks).*

*“...everybody here knows that we are all going through the same problems so nobody is looking at you or judging you and wondering what is wrong...they know exactly what you are going through...” (Participant 17, interviewed at 6 weeks).*

*“I think the girls are easier to talk to because they have been through it and obviously the staff have seen it all but I find it easier to talk to them” (Participant 19, interviewed at 7 weeks).*

Two participants felt a lack of support from their peers. Linking to the previous theme “loss of normality”, participant 6 experienced difficulties with her peers in treatment due to continuously sharing a living environment with people in distress.

*“When I first came in and it was good to be around people who had the same thoughts and same feelings but now I almost feel I have had enough. I feel is it ever going to end...I would like to be...with normal people” (Participant 6, interviewed at 28 weeks).*

Participant 6, who has been an inpatient for the longest duration out of the sample, perceives peer support in the unit as less valuable as her desire to re-engage with the outside world grows.

In contrast, participant 14 expresses her difficulties of having to cope with dishonesty and negative attitudes amongst her inpatient peers.

*“It is really hard because there are a few people who are really horrible... you can tell they lie about their eating habits and lie about stupid things. It is like being in the Big Brother house it is a bad atmosphere to be in” (Participant 14, interviewed at 12 weeks).*

#### **4.2.4.2 Learning from peers**

Linking with the previous theme, “I am not alone – benefits of peer support”, participants discussed the different influences that their peers had on their treatment progress. Sharing the treatment environment with peers enabled participants to learn positive examples from peers who had progressed in treatment. This appeared to encourage participants to re-evaluate the impact of their eating disorder on their life, providing knowledge of effective coping skills and a sense of hope for recovery.

*“... it is really good in terms of being able to hear how other people have gotten over, how they have gotten over the drive to exercise and how they have managed to eat certain foods. How did they cope with it and what did they do?” (Participant 3, interviewed at 20 weeks).*

*“...for me to have people who are so far on in treatment and getting well...they have all been through different things and you learn so much and hear so many stories...”(Participant 11, interviewed at 2 weeks).*

However, some participants also identified the negative influence of peer behaviours in treatment. Participants became more aware of and susceptible to adopting unhelpful eating behaviours. This led to increased feelings of worry and distress. An exemplar of this is provided by Participant 17:

*“...sometimes if a particular food or something in particular that someone was really worried about and I never thought about it before... seeing them worry about it would make me think I should worry about it so they can sometimes put things in your head...”(Participant 17, interviewed at 6 weeks).*

#### **4.2.4.3 Envy of emaciated peers**

Some participants spoke of comparing themselves to their peers throughout treatment. Participants spoke about how they frequently compared their own physical appearance

to that of their peers, particularly those who had recently been admitted into treatment. They also described comparing their eating behaviours with their peers in treatment, acknowledging their fears at being perceived as “greedy” when eating meals alongside those who struggled at meal-times. This often resulted in feelings of inadequacy, guilt at recovery and a desire for further weight loss.

*“...you spend a lot of time comparing yourself to your peers physically. I constantly had a real need to be emaciated again...I felt very envious of them and...the drive to be that way became more intense” (Participant 3, interviewed at 20 weeks).*

*“...it is hard when you are eating meals and people are not finishing them. You feel greedy”. (Participant 7, interviewed at 12 weeks).*

*“It is really hard especially when I am at the weight I am just now and there are people coming in and they are emaciated...it really affects me because I cannot speak to them or look at them because my eating disorder is thinking I want to be like that...” (Participant 14, interviewed at 12 weeks).*

One participant described the sense of competition amongst her peers and her comparison of her illness to those who had prior admissions. Her account is characterised by feelings of failure and the desire to relapse in order to become more deserving of treatment than her peers.

*“It is hard for people when they come in and saying I was in before...it is like they are bragging... It makes you feel although I haven't been in before maybe that means I am not such as bad anorexic and I need to go home and start relapsing” (Participant 14, interviewed at 12 weeks).*



#### **4.2.4.4 Coping with others' distress**

Some participants spoke about the difficulties of living alongside peers who were unmotivated or distressed during treatment. For example, some participants reported witnessing episodes of self-harm and aggressive behaviour. Participants described feeling scared and worried at seeing their peers struggle within treatment.

*“Having to experience other people’s distress because of their issues is hard, people being upset and at times been very out of control and people self-harming, people screaming out in the night” (Participant 3, interviewed at 20 weeks).*

*“...if other people are down and you are trying to be positive or if there is a general level of “oh things are rubbish”, you think “oh Jesus!” (Participant 18, interviewed at 5 weeks).*

One participant spoke of a sense of unfairness in relation to peers who received more attention than others due to their distressed state.

*“I think sometimes you can see people who kick up a bit of fuss get the most. Get the most attention whereas the people who are quiet and let things go, get overlooked...” (Participant 5, interviewed at 20 weeks).*

Two participants discussed their dislike of having to support peers in distress. Linking with the previous theme “perceived inconsistencies in staff support”, these participants perceived a lack of staff support in the unit, leading to an increased sense of responsibility for supporting their peers during difficulties. Such perceptions led to feelings of stress, disrupting their sense of focus on their treatment.

*“...we are encouraged to support each other... sometimes it feels as if we are the only ones offering support and are taking that burden onto*

*yourself so it means it doesn't help ourselves as we get quite stressed" (Participant 11, interviewed at 2 weeks).*

*"Everybody has their own problems, they are all exploding at some point...it is something I feel I do not have to be dealing with. I would rather be focussing on my treatment in a more stable environment..." (Participant 15, interviewed at 16 weeks).*

#### **4.2.5 Process of recovery and self discovery**

The final master theme, "process of recovery and self discovery", represents participants experiences of recovery and the growing sense of self awareness in treatment. This master theme is comprised of three themes: (1) recovery as an arduous process: contrast between physical restoration and AN recovery; (2) role of self-motivation; and (3) self discovery and regaining confidence.

##### **4.2.5.1 Recovery as an arduous process: contrast between physical restoration and AN recovery**

Most participants discussed their feelings in relation to their current stage of recovery from their eating disorder in treatment. The recovery process was characterised by an emotional and physical struggle to overcome their eating disorder. An exemplar of this is provided by Participant 4:

*"Just the upset. You are fighting the eating disorder and having to put up with increases in your menu plan and you are constantly full. Me, I feel sick and constipated, feel tired and your emotions are everywhere..." (Participant 4, interviewed 20 weeks).*

There was a strong suggestion that recovery was not a simple process and that it would involve the continuous awareness and management of residual symptoms beyond

treatment. While most participants felt they were making progress with their nutritional and weight restoration, they continued to experience maladaptive beliefs about their eating, weight and shape.

*“...each time I eat I then have to deal with the thoughts... That is still about but to a much lesser extent, a more manageable stage...So the thoughts are still there but I am not acting upon them...” (Participant 3, interviewed 20 weeks).*

*“I am still struggling and it is hard...I want to get better and I still have the negative thoughts on the eating disorder... It has been slow but it is still difficult. I still struggle” (Participant 19, interviewed at 7 weeks).*

*“It is still quite difficult. I had a terrible day yesterday because I went to put my jeans on and my head was saying they are going to be so tight when on you but it is getting less...” (Participant 21, interviewed at 2 weeks).*

Participants felt that they were gradually learning to manage these maladaptive beliefs, however their accounts compounded a need for persistence to remain on the “process” of recovery. It would seem from their accounts that these participants felt their psychological recovery from their eating disorder would take longer than their physical recovery.

#### **4.2.5.2 Role of self-motivation**

Some participants spoke of their readiness and motivation for change. A few participants strongly asserted that self-motivation was necessary for treatment acceptance and recovery. Like the previous theme, “recovery as an arduous process: contrast between physical restoration and AN recovery” participants felt that

superficial recovery (i.e. weight re-gain) could occur easily but that “real change” required a personal willingness to address all factors relating to their difficulties.

*“I made a deal with myself if I came back to inpatient treatment it had to be all or nothing...I knew this time if I did not come in and commit 100% there was no point because your recovery would not happen...”(Participant 3, interviewed at 20 weeks).*

*“I am ready to change this time and unless you are ready to change I do not think it can work. You can go through the motions quite easily and put on weight and not change and that is what happened to me the last time” (Participant 4, interviewed at 20 weeks).*

#### **4.2.5.3 Self-discovery and regaining confidence**

Some participants described a growing awareness of a sense of self throughout treatment, which was felt to be helpful for recovery. Reference was made to the process of separating themselves from their eating disorder and re-discovering their self-identity. This led to increased feelings of self-awareness and self-confidence. Linking to the previous theme “regaining control” participants felt that finding their own identity in treatment allowed them to regain greater control over their anorexic symptoms and facilitated the identification of activities to replace the function of their eating behaviours.

*“...I think I have grown up as a person...I feel I can take control of my life now and am more independent...its definitely built my confidence and independence...”(Participant 2, interviewed at 24 weeks).*

*“I find it difficult to distinguish what is real, what is me and what is the eating disorder...a lot of what my treatment has been this time*

*is actually separating and finding my own identity separate from the eating disorder” (Participant 3, interviewed at 20 weeks).*

*“I am getting character in myself again and finding a personality and it is all coming back to me who I want to be but getting there is really difficult...” (Participant 15, interviewed at 16 weeks).*

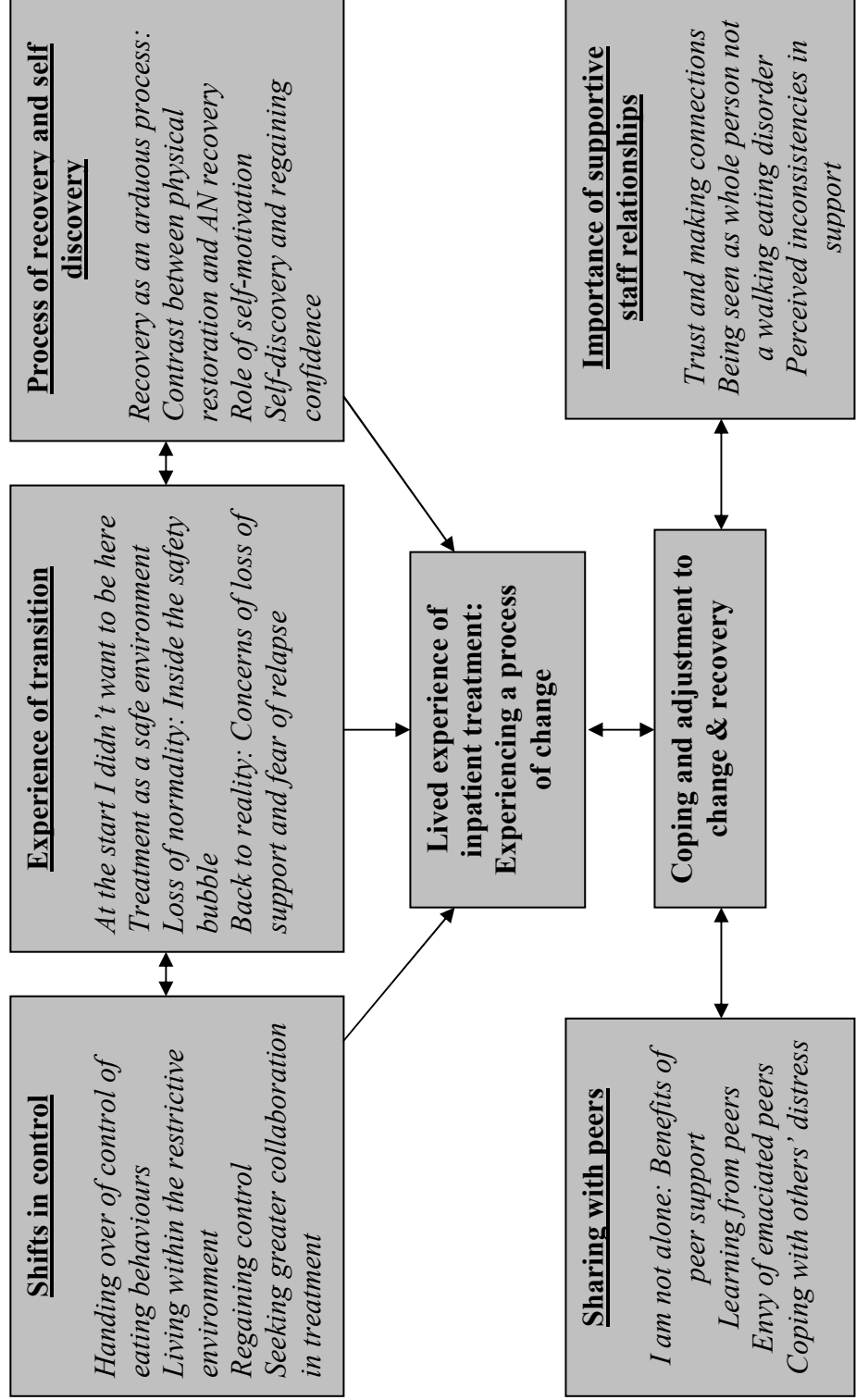
### **4.3 Relationships between master themes**

Smith *et al* (2009) recommend that the researcher should connect the master themes to move the data to a more theoretical level. Smith *et al* (2009) also suggest presenting the interconnections between the master themes graphically when using IPA with larger samples.

In moving from a description of the 5 master themes, the researcher hypothesised possible relationships between the themes. While the master themes represent distinct aspects of participants’ perceptions of inpatient treatment for AN, the researcher noticed that they each involved a process of adjusting to and coping with a sense of “change”. Participants’ descriptions seemed to suggest that they experienced changes in their level of perceived personal control, attachment to the treatment environment and a sense of self-identity separate from their anorexia. Treatment represents “shifts in control”, as participants have to cope with initially handing over control of their eating behaviours within a restrictive environment as a step towards restoring feelings of self-competency and self-control. “Experiences of transitions” between the home environment and the inpatient setting have an impact on participants’ appraisal of treatment, as they have to cope with a loss of normality and then the separation of the “secure base” of treatment upon reaching physical recovery. Themes of the recovery

process also impact on the experience of inpatient treatment. Participants have to cope with making changes to their anorectic behaviours while trying to re-establish a greater sense of self. Participants' abilities to cope with these perceived changes appear to be directly influenced by the development of relationships with staff and their peers in the unit. This is bi-directional as it was hypothesised that the experience of change throughout treatment may also influence the appraisal of relationships. It was interpreted that supportive peer and staff relationships within the unit, enabled participants to be more confident in disclosing personal difficulties in treatment and to learn adaptive coping skills. Negative experiences of sharing treatment with peers and support inconsistencies of staff were more likely to increase vulnerability and difficulties in coping with the demands of treatment and recovery.

These relationships are presented in Figure 4.1.



**Figure 4.1:** Identified master themes and sub-ordinate themes relating to participants' experiences and meaning of inpatient treatment for anorexia nervosa

## **4.4 Reflections on findings**

### **4.4.1 Researcher's reflections**

Smith *et al* (2009) recommend that researchers using IPA should clearly reflect upon their position within the research process, as the researcher is required to provide an interpretation of participant accounts, which may be influenced by their own knowledge and experience. The researcher utilised a reflexive diary in the current study to record experiences and feelings throughout the research process allowing transparency of her assumptions, experiences, knowledge and beliefs. The following section is written in the first person to reflect the language used within the diary and is illustrated with extracts from this diary.

I initially felt apprehensive and anxious in the early stages of the current study due to my inexperience in conducting qualitative research. The first few interviews were difficult as they differed from my clinical sessions with patients during training and I was conscious of the need to distance myself from “leading” questions when trying to gather descriptions of participants’ experiences. I felt an overwhelming sense of responsibility within the interview to gather as much information as possible to represent their accounts fully. The following diary extract details my initial anxiety about using a qualitative approach.

*“...completed my first two interviews today, I found today overwhelming! I’m not sure whether I am gaining enough description of participants’ experiences... but I don’t want them to feel like I am overly pushing them for information. I am trying not to turn into therapist mode and make hypotheses but it is difficult not to...” (Extract 1).*



However, my confidence grew as the interviews progressed and I began to enjoy the interview process. I found myself achieving a balance between directing the interview and allowing participants flexibility to discuss experiences that they felt were relevant. I became less anxious about my interview approach and began to reflect more on the participants' experiences linking this to my own clinical experiences in working with patients with AN.

*“...building a therapeutic relationship with staff on the unit appears to be a common theme. I feel a little concerned at the reports of the participants feeling unsupported at times...Some of the participants talked about staff assuming all their behaviours to be related to their eating disorder... I feel a bit ashamed that I thought some of their descriptions were related to their anorexia. I wonder how often I do this with my patients back home? Do I make assumptions?” (Extract 2).*

As I met with participants, I wondered whether my role as a female psychologist would impact on their ability to talk honestly about their treatment experiences. I felt that my clinical training enabled me to establish rapport quickly with participants. However, I remained aware that I was a stranger to them and that they may have perceived me as being part of the staff team within the eating disorders unit.

*“I am really enjoying the interviews so far and find it so interesting to hear how participants are experiencing the unit. They appear to be quite forthcoming about their treatment difficulties but I do wonder if they are being honest? Do they see me as part of the unit and or as someone who could influence their treatment?” (Extract 3).*

I tried to elicit honest descriptions of participants' treatment experiences by discussing their rights to confidentiality and my external training position. I found

that by explaining my role in the current study, participants felt at ease during the interviews and were able to describe both positive and negative experiences.

As I began my analysis, I was aware of my large sample and felt anxious about summarising the gathered descriptions while representing individual views. I felt worried that I would overlook key experiences or that my clinical experiences from my training would cause me to unconsciously develop themes that were not derived from participants' accounts. I began to question whether my work within outpatient settings made me focus more on themes relating to the transition between inpatient and outpatient services. I felt concerned that I was looking for specific experiences in relation to this and overlooking what participants were trying to convey.

*“Themes of transition between services and the accessibility of specialist services keep emerging in the interviews so far. This is really similar to my own patients' accounts of difficulties managing their eating difficulties at home... One patient on my caseload is really struggling at the moment and needs more intensive meal support than I can provide...How much am I referring to my own patients' experiences into my interpretations?” (Extract 4).*

I felt overwhelmed with the amount of data that resulted from the interviews. I was aware of my need to maintain an interpretative stance and continually sought different ways of interpreting the data by frequently moving between the developing themes and the original transcripts. Discussions with my supervisors and my peers within the qualitative support seminars helped me to critically evaluate my interpretations.

*“Feeling a lot more confident in my interpretation of the findings after speaking with my supervisors about how to cluster the super-ordinate themes. It really helps just to discuss my ideas...” (Extract 5).*

Overall, the research process highlighted my anxiety at trying to accurately represent the complexity of participants' experiences of inpatient treatment. Throughout the research process, I gradually developed a confidence in my interpretations and an acceptance that complex experiences do not lend themselves to one absolute interpretation. Over time, I felt that I became a platform for participants to voice their often previously "unheard" views of their treatment.

#### **4.4.2 Participants' reflections**

Participants were asked to reflect on their experience of the interview process. All participants felt their involvement in the research was a positive experience and allowed them to reflect on their treatment experiences.

*"...it is putting things into more perspective...what is best for me and what is not...So speaking about this has actually helped to put it into perspective..." (Participant 15, interviewed at 16 weeks).*

*"I thought it was quite useful actually. It is nice to be asked...this is something that doesn't get done in all of the tests so it feels quite empowering" (Participant 18, interviewed at 5 weeks).*

Following completion of the data analysis, the researcher also sought respondent validation of the findings. As all of the participants were discharged from the inpatient unit during the research process, the researcher presented a summary of the findings to a different group of four, adult female inpatients who were undergoing active treatment for AN within the unit. The group were asked to review the credibility of the identified themes in relation to their experiences of the inpatient treatment programme.

All of the group expressed their agreement with the themes and they felt that the current study provided a good description of their treatment experiences. An exemplar of this is provided by one patient:

*“You have definitely got a good grasp of it...if you were telling someone just off the street that would be a good indicator of how it is...”(Patient 1).*

The group discussed their own experiences of the inpatient eating disorders unit in relation to the identified themes, highlighting similar experiences to the participants who were interviewed. For example, in relation to the master theme, “shifts in control”, the group discussed their experiences of changes in their levels of perceived control during treatment and the importance of this for their recovery. An example of this is provided by another patient:

*“...it’s like being a child again you have no control over anything but I think deep down in order to get better you need to have no control...you have to give it all away because you are not going to get better otherwise” (Patient 2).*

Some patients in the group also attributed different meanings or interpretations of the identified themes. For example, linking to the sub-ordinate theme “envy of emaciated peers”, patient 3 spoke of how she compared her appearance and her progress in treatment to that of her peers. However, she described how she had felt more envious of her peers who were further into their recovery rather than those who were newly admitted and struggling in treatment. This resulted in her increased motivation to engage with treatment.

*“You always think I want to be thinner...but you get to the stage where you think I’m glad to be getting better...I was more envious of girls going out on passes.....it made me more motivated” (Patient 3).*

The researcher acknowledges that there is a risk that the small group of patients may have different views and experiences of treatment than the original participants who were interviewed. There is also the possibility that individuals’ in the group were reluctant to disagree with the researcher or their peers during the group feedback session. However, the feedback from the focus group generated good support for the identified themes in the current study and the researcher’s interpretation of the participants’ treatment experiences.

A summary of the findings of the current study was also sent out by post to the original participants (see Appendix 11). No feedback was received from participants after they were sent a summary of the findings.

## **5. DISCUSSION**

This chapter will begin with a summary of the current study. Reflections on each master theme will be provided with reference to the relevant literature including studies previously reviewed in the Systematic Review of this thesis. Implications of the current findings for theory and clinical practice will be outlined, with areas for future research discussed. Following this, the methodological strengths and limitations of the study will be considered.

### **5.1 Summary of results**

The aim of the study was to explore the nature of adult female patients' lived experience of specialist inpatient treatment for AN and the treatment factors that may influence their recovery process. Twenty-one female participants with a diagnosis of AN took part in the current study. The age of participants ranged from 18 to 43 years. Participants were recruited from a specialist inpatient eating disorders unit situated within the independent sector, which had an established referral pathway with both independent healthcare organisations and NHS health boards. The length of participants' current admission within the eating disorder unit ranged from 2 weeks to 7 months.

Analysis of the transcripts revealed five master themes, which the researcher felt reflected the structure of the participants' experiences. The first master theme "Shifts in Control" represents the continuous change in levels of perceived control throughout treatment and the meaning that this had for participants. The second master theme "Experience of Transition" relates to the process of coping with a sense

of environmental transition throughout treatment. This includes the initial transition into the inpatient treatment environment, the growing sense of adjustment versus the awareness of a loss of normality as treatment progresses and the perceptions of life and recovery following discharge. The third master theme “Importance of Supportive Staff Relationships” reflects participants’ perceptions of staff support in treatment and the impact of this on the treatment process. The fourth master theme “Sharing with Peers” relates to the positive and negative influences of peer relationships in treatment. The final master theme “Process of Recovery and Self-discovery”, represents participants’ experiences of recovery and the growing development of self-awareness in treatment.

Overall, the master themes reflect the experience of “change” throughout treatment. The frequency of conflicting feelings and attitudes towards the treatment process highlights the complexity of the treatment experience and the adjustment process. Participants’ sense of adjustment and ability to cope with the challenges of treatment were shaped by the development of supportive relationships, and effective responses to individual care needs.

## **5.2 Reflections on master themes**

### **5.2.1 Reflections on “Shifts in Control”**

Consistent with earlier work (Offord *et al.*, 2006), participants’ narratives suggest a change in levels of perceived personal control when entering inpatient treatment. Some participants described that they had already lost personal control of their eating behaviours to their anorexia, prior to treatment. They perceived treatment as “handing over” their responsibility to control their eating disorder behaviours and felt relief

from their endless preoccupation with ritualised routines. In contrast, a few participants perceived having their sense of personal control “taken away”, leaving them feeling vulnerable. This suggests that the way in which patients perceive the initial change in levels of personal control in inpatient treatment has a direct impact on their ability to cope. A recent study by Sternheim, Konstantellou, Startup and Schmidt (2010) supports this theme, finding that patients with AN reacted very negatively towards feelings of reduced personal control, describing it as a personal threat and remaining vigilant to negative outcomes. Additionally, Eviors *et al* (2003) highlighted patient perceptions of lost control in treatment were influenced by an imposing approach and the inappropriate timing of treatment. Patients felt that disengaging from treatment enabled their re-assertion of control over their life.

The current study suggests that where there is a sense of handing over of control when entering treatment (or having a sense of some power over the transfer of control), rather than a perception of loss of control, this seems to be associated with a difference in attitude towards the treatment process. For some participants, the reduction in personal control in treatment *can* be viewed positively. Having the ability to transfer control from their anorexia to staff within the unit, could be seen as an interim step towards re-establishing self-control.

As found in studies of adolescents’ views of inpatient treatment for AN (e.g. Colton & Pistrang, 2004; Offord *et al.*, 2006), participants in the current study described conflicting feelings towards the high level of structure and supervision in the inpatient treatment environment. Most participants expressed a dislike of the restrictive environment, while acknowledging that this was necessary to facilitate recovery and



prevent their engagement in their eating disorder behaviours. Some participants felt the restrictive treatment environment allowed them to challenge their fears of releasing control. Similar to previous research, the restrictive aspects of treatment were viewed more positively if delivered within a supportive environment (Colton & Pistrang, 2004; Griffiths *et al.*, 1996; Offord *et al.*, 2006; Tan *et al.*, 2003; Tan *et al.*, 2010).

The sub-ordinate theme “Regaining Control” highlights the process of participants gradually regaining a “normal” level of control during treatment and the emotional impact of having their initial restrictions reduced. Participants discussed feelings of empowerment at gaining choice and a greater sense of control over their eating behaviours over time. The reduction of restrictions promoted a sense of having trust re-established from others and added to feelings of self-confidence. The current study adds to the understanding of the process of developing increased control and choice throughout inpatient treatment, which was not highlighted in Offord *et al.*'s (2006) earlier study.

Participants felt that greater patient involvement in treatment decision making would enable care to be matched to individual needs and may result in improved patient acceptance of treatment recommendations. Similar to previous studies (Colton & Pistrang, 2004; Offord *et al.*, 2006), some participants spoke about their difficulties in having their views listened to in treatment, which resulted in feelings of frustration, disempowerment and confusion. The importance of involving patients within treatment planning has previously been identified, with treatment practices seen as inflexible and authoritarian leading to disengagement from treatment (e.g. Darcy *et*

*al.*, 2010; Eviors *et al.*, 2003; Offord *et al.*, 2006; Van Ommen *et al.*, 2009). Practices which encourage patient collaboration in treatment have been found to enhance the therapeutic environment and increase patients' sense of preparation for life following discharge (Offord *et al.*, 2006; Van Ommen *et al.*, 2009).

### **5.2.2 Reflections on “Experience of Transition”**

Narratives in the current study indicate the challenges associated with the transition into the inpatient treatment environment. The early weeks of inpatient treatment were a time of intense emotional distress as participants tried to adjust to their removal from their home environment. Some participants felt being removed from everyday life stressors enabled them to focus on their recovery. However, other participants felt that this prevented them from achieving recovery in a “normal” environment resulting in concerns of relapse while re-adjusting to outside life following discharge. As reported in Offord *et al* (2006) feeling removed from a sense of “normality” in treatment resulted in a longing for normalising social activities and the development of life-skills as preparation for discharge.

The current study adds to the understanding of the complexity of patients' experiences of treatment as participants reported that inpatient treatment offered protection from life stressors, providing a sense of familiarity and structure. As Fennig, Fennig and Roe (2002) highlight, the treatment environment becomes a safe, containing base for participants to challenge their AN, without perceived pressures of family and the outside world. In line with findings by Tierney (2008), inpatient treatment was referred to as a life-saving event. Participants perceived their inpatient stay as essential for recovery due to the provision of intensive support, which was

rarely provided in outpatient services. This sense of attachment led to a gradual fear of losing the level of support and structure following discharge and a wish to remain as an inpatient. Vandereycken (2003) highlights the difficulties of the transition from hospital to home and the pattern of readmission due to the patient's poor emotional readiness for discharge. Fennig *et al* (2002) compare the process of the transition home to a child's separation-individuation stage of development, suggesting the need for exposure to daily activities in the community to prepare for discharge and the subsequent separation from the security of the inpatient treatment environment.

Perceptions of the re-adjustment from the treatment environment to outside life were influenced by fears of differences in the level of outpatient service provision and support following discharge. Over half of participants in the current study had a history of previous inpatient admissions for AN, and had experienced previous difficulties at accessing outpatient support. Research has indicated that patients with eating disorders may experience difficulties accessing appropriate care due to the regional inequities of specialist outpatient service provision and delayed diagnosis by general practitioners (Escobar-Koch *et al.*, 2009). Experiences of poor transition planning and follow-up care after discharge appeared to affect participants' abilities to re-adjust to life outside the hospital environment. Qualitative research with adolescents with AN has found similar negative experiences of service transitions (Arcelus, Bouman & Morgan, 2008; Offord *et al.*, 2006). Arcelus *et al* (2008) suggest that the lack of clear procedures for managing the transfer of patient care between services can lead to reductions in the level of support given to patients, placing them at greater risk of relapse. Consistent with Offord *et al* (2006), participants in the

current study noted that the establishment of continued support following discharge was important to prevent relapse.

### **5.2.3 Reflections on “The Importance of Supportive Staff Relationships”**

Participants highlighted the importance of receiving supportive staff relationships within treatment. Participants’ accounts focussed on their perceptions of the *process* of delivery of treatment rather than the specific treatment modalities. This indicates that participants perceived staff factors or treatment processes as more important in their experience of treatment than the actual treatment modalities. This is consistent with a previous review of treatment perceptions in eating disorders, which found the delivery of eating disorders treatment within a supportive therapeutic relationship was as important as the content of treatment programmes (Bell, 2003).

In the current study, participants described varying experiences of staff support within the unit. They felt it was important to receive support from staff who listened to their views and who were able to recognise when they required support. These findings have been widely reported in the eating disorder literature, which highlights the importance of good communication, understanding, reliability, respect for individuals’, physical and emotional availability and firmness (e.g. De la Rie *et al.*, 2008; Le Grange & Gelman, 1998; Reid *et al.*, 2008; Van Ommen *et al.*, 2009). Similar to other studies (e.g. Colton & Pistrang, 2004; Darcy *et al.*, 2010; Whitney *et al.*, 2008) the current study found that participants expressed difficulties with accessing staff support, negative staff attitudes and approach inconsistencies in treatment. As found in Darcy *et al* (2010), dissatisfaction with the therapeutic approach led to a reduced motivation to engage with treatment.

Of particular note in the current study is that some participants explicitly referred to the gradual development of trusting relationships with staff that enabled help seeking behaviours in treatment. Participants felt the development of trusting relationships with unit staff was facilitated through the provision of person-centred care, which was sensitive to participants' individuality and personal support needs. Participants described the importance of receiving individual therapy sessions to discuss their psychological and emotional issues related to their eating disorder. In contrast, participants felt a sense of frustration at staff who they perceived as failing to consider their individual needs in treatment. They reported feeling frustrated at staff for making assumptions about their behaviour as being directly attributable to their eating disorder than being due to an alternative causation. Staff difficulties at determining the differences between individual preferences and anorexic behaviours has also been highlighted in previous studies carried out with adolescent patients with AN (Colton and Pistrang, 2004; Offord, *et al.*, 2006). In these studies, feeling labelled as an "anorexic" led to an increased sense of being misunderstood.

While recognising the need to regain weight, participants felt they were at greater risk of relapse following discharge if treatment neglected their individual psychological and emotional needs. Previous eating disorder research has noted increased patient satisfaction with treatment which incorporated a holistic approach (e.g. Button & Warren, 2001; Colton & Pistrang, 2004; Eviors *et al.*, 2003; Federici & Kaplan, 2008; Le Grange & Gelman, 1998; Newton *et al.*, 2003; Offord *et al.*, 2006; Tierney, 2008; Vandelinden *et al.*, 2007; Whitney *et al.*, 2008). In the current study, the lack of recognition for progress not related to weight gain led to a reduction in motivation to continue in treatment. Eviors *et al* (2003) argue that the imposition of a solely

physical symptom focussed approach allows the continuation of anorectic thinking around food, resulting in a further loss of perceived control and a greater desire to disengage from treatment to regain feelings of control. Similarly, Federici and Kaplan (2008) suggest the neglect of psychological issues in treatment can leave patients feeling ill equipped for discharge and at greater risk of re-engaging with their eating disorder behaviours as a coping strategy to manage life stressors.

#### **5.2.4 Reflections on “Sharing with Peers”**

In their experiences of inpatient treatment, all participants spoke about the ways in which living alongside others who had eating disorders influenced their adjustment to treatment and recovery. For the majority, living with other patients with eating disorders, particularly AN, in treatment led to increased feelings of peer support and acceptance. The sharing of experiences appeared to encourage some participants to re-evaluate the impact of their eating disorder on their life, providing knowledge of effective coping skills and making recovery seem achievable. The value of peer support in the current study is consistent with the adolescent eating disorder literature, which found that peer support reduced feelings of isolation and was perceived as more helpful than professional support (Colton & Pistrang, 2004; Offord *et al.*, 2006; Tierney, 2008). Indeed, some participants in the current study noted that they often felt that their peers were the only people who could fully understand their difficulties.

However, for some participants, living alongside patients with eating disorders in treatment also led to increased self-comparison, competition and distress, as reported elsewhere (Colton & Pistrang, 2004; Offord *et al.*, 2006; Tierney, 2008). At times, comparisons with the physical appearance and behaviours of their peers strengthened

their existing eating disorder beliefs and led to an increased awareness of new eating disorder behaviours. Some participants revealed how living alongside peers in visible distress disrupted their sense of focus on their own treatment. In the current study, negative experiences were particularly associated with the arrival of newly admitted patients, who served as reminder of their previous anorexic state. This led to feelings of envy of the emaciated state of newly admitted patients and guilt at their own weight gain. Patient experiences of new patient admissions have been associated with an increased desire to lose weight and fears of being perceived as greedy at mealtimes (Tierney, 2008). More specifically, Darcy *et al* (2010) argue that the difficulties of living alongside other patients including living with peers of different ages could lead to increased levels of treatment dissatisfaction.

#### **5.2.5 Reflections on “The Process of Recovery and Self-Discovery**

Participant narratives suggest that the recovery process in treatment was characterised by a continuous struggle to overcome their eating disorder. Of particular importance was that participants perceived the process of psychological recovery as requiring more time than physical recovery, i.e. weight restoration. This theme is consistent with the findings of previous research (e.g. D’Abundo & Chally, 2004; Federici & Kaplan, 2008; Fennig *et al*, 2002; Granek, 2007; Tierney, 2008). In Federici and Kaplan’s (2008) study of relapse and recovery, former patients who had recovered continued to perceive their recovery as a struggle, requiring persistence and vigilance to signs of relapse. In contrast, patients who relapsed following treatment noted their lack of anticipation about the effort required to sustain recovery. Similarly, Fennig *et al* (2002) argue that full recovery from AN requires both physical and psychological

recovery and that discontinuation of treatment following weight regain but not psychological recovery can result in poor prognosis and relapse.

Of particular significance is participants' acknowledgement of the necessity of self-motivation to facilitate treatment acceptance and the recovery process. Participants reported that they had to want to recover for treatment to be successful. This finding relates to a number of studies in the eating disorder literature, which indicates a readiness to change as an important contributing factor to patients' recovery (Colton & Pistrang, 2004; Federici & Kaplan, 2008; Hsu *et al.*, 1992; Pettersen & Rosenvinge, 2002; Tierney, 2008). In the current study some participants expressed their desire to pursue life goals such as returning home to their children, which resulted in an increased motivation to engage with treatment. D'Abundo and Chally (2004) found that recovery in eating disorders was enhanced by hope for the future and the desire to engage in life activities such as college and relationships. In contrast, a reduced motivation to recover in treatment was related to continued use of eating disorder behaviours following discharge (Federici & Kaplan, 2008; Tierney, 2008).

Prior to treatment, participants described feeling that their anorexia had become their identity. Similar to these participant narratives, previous research has highlighted that individuals construct and acquire an alternative sense of identity through their anorexia, replacing their own "fragile" self-identity (Epsindola & Blay, 2009; Norbo, Espeset, Gulliksen, Skarderud & Holte, 2006). Of particular note in the current study is that participants explicitly reported a growing awareness of a sense of self throughout treatment. Inpatient treatment provided an environment where participants were able to embark on a process of self-discovery, re-establishing a self-identity not



characterised or governed by their anorectic behaviours. Granek's (2007) study of recovery in AN, highlighted that the subjective experience of recovery from AN involved the re-establishment of self-worth separate from weight loss. Thus, it may be that treatment provides a sense of confidence and self-worth, allowing the reconstruction of their self-identity and lowered reliance on their anorexic identity.

### **5.3 Implications for clinical practice**

Based on the themes identified in the current study and discussions with participants, a number of recommendations can be made for clinical practice and service provision for patients with AN.

The focus of narratives on experiences of the staff approach rather than the treatment content highlights the need to direct increased attention to *how* treatment is delivered. The themes reflect the need for improvements in the delivery of treatment by health professionals. These findings support previous research emphasising the need for increased awareness and reconsideration of current professional practices (e.g. Bell, 2003; Colton & Pistrang, 2004; Offord *et al.*, 2006; Reid *et al.*, 2010). Many health professionals working in eating disorder services acknowledge their level of training and knowledge as inadequate, negatively impacting their therapeutic abilities (Reid *et al.*, 2010). Consistent with these findings, there is a recognised need for improved professional training in eating disorders to facilitate successful treatment outcomes (NICE, 2004; NHS QIS, 2006; Scottish Executive Health Department, 2001). This can be established through health professionals attending accredited specialist training programmes in eating disorders such as those run by Eating Disorder Education and Training Scotland.

Consistent with previous research, treatment experiences were influenced by the quality of staff interactions with emphasis placed on therapist qualities which promoted a supportive and trusting therapeutic environment (Fuertes *et al.*, 2009; Kaplan & Garfinkel, 1999; Mostow *et al.*, 2010; Vanderlinden, 2007). However, the value of non-specific therapeutic skills can often be underestimated in treatment, suggesting the need for health professionals to reconsider the use of relational models in clinical practice to facilitate a strong therapeutic alliance. Bamford and Mountford (2010) suggest that clinicians should focus primarily on engagement and providing consistent support. Even medical professionals who are focussed on reduction of physical symptoms can also establish a working relationship with patients through the demonstration of empathy and understanding (Tierney, 2008).

Clinical psychologists have extensive training in core therapeutic skills and are in a key position to deliver training on fostering a strong therapeutic alliance to professionals working with patients with eating disorders. Recent therapeutic programmes have been developed for health professionals working with patients with AN, which focus on developing a supportive therapeutic context in treatment (Bamford & Mountford, 2010; McIntosh *et al.*, 2006). In particular the Specialist Supportive Clinical Management (SSCM) programme encourages weight restoration and symptom reduction through attending to the maintenance of key therapeutic and clinical management skills (McIntosh *et al.*, 2006). Clinical psychologists may wish to explore these models in their own clinical practice and provide training on these treatment programmes to other clinicians. In addition, given that some participants spoke about experiencing negative professional attitudes, there is a need for health professionals to seek supervision and reflect on their own clinical practice. Health

professionals should specifically reflect on whether they may be imposing their own assumptions of AN on patients, albeit inadvertently. This is important in light of evidence that an inability to differentiate individual differences from anorexic traits can lead to patient perceptions of professional insensitivity (Colton & Pistrang, 2004; Offord *et al.*, 2006). Clinical psychologists are trained in supervisory skills and can provide clinical supervision to staff to encourage and foster reflective practice.

An analysis of participants' narratives suggests the importance of providing individualised and collaborative care in treatment. In light of the fact that some participants experienced a loss of perceived control, it follows that health professionals should allow for greater patient collaboration within treatment. The ability to attend hospital review meetings and the receipt of regular feedback on progress could help to reduce feelings of uncertainty. Unpopular yet necessary treatment practices, such as restrictions may be helped by the provision of educational information about the utilisation of the treatment strategies and increased opportunities for patient collaboration in treatment goals. Clinical psychologists can provide advice or work alongside other staff to develop case formulations in collaboration with each patient to encourage a collaborative treatment plan (Lavender & Schmidt, 2006). Allowing flexibility with the pace and designation of specific restrictions in relation to individual treatment needs may increase patients' levels of perceived personal control in treatment

Participants also valued individual therapy sessions which addressed the psychological factors underlying their condition. As seen in previous research, interventions that only focus upon weight restoration can result in increased patient

frustration and are unlikely to produce effective long-term outcomes (Colton & Pistrang, 2004; Espindola & Blay, 2009; Offord *et al.*, 2006; Slade, 1982). Increased recognition of individual psychological needs in treatment may help to increase acceptability of aspects of treatment such as weight regain, which are perceived less favourably. The findings suggest there is a need for greater access to psychological therapies, which focus on improving quality of life and are tailored to patients' support needs. The current study highlights the difficulties of achieving psychological recovery from AN during treatment. This suggests the need for clinicians to look to models of recovery in which individuals are supported to achieve improvements in their quality of life even in the presence of chronic symptoms (Brown & Kandirikirira, 2007). Bamford and Mountford (2010) suggest that therapeutic interventions for individuals with severe and enduring AN should specifically focus on psychological rehabilitation strategies such as skills training, goal planning and motivational enhancement to increase appropriate coping skills for discharge.

As participants' acceptance of treatment appeared to be influenced by their motivation to address their eating disorder behaviours, it follows that the provision of motivational strategies in the treatment of AN is paramount. The application of the trans-theoretical model of change (Prochaska & DiClemente, 1982) has been explored in the eating disorder literature, with findings suggesting that motivation to change can predict treatment outcome in patients with AN (Amettler *et al.*, 2005; Casasnovas *et al.*, 2007; Reiger *et al.*, 2000; Serrano *et al.*, 2004; Tierney, 2008; Treasure & Schmidt, 2001. As Garner, Vitousek and Pike (1997) highlight it is important for health professionals to be aware of the fluctuating nature of motivation within eating disorders and to sensitively match this to treatment goals. The

utilisation of motivational interviewing can help patients to become more aware of the benefits and drawbacks of their treatment, allowing them to refocus on their initial treatment goals (Colton & Pistrang, 2004). Clinicians utilising motivational strategies as part of a psychological rehabilitation programme should acknowledge the reality of the impact of AN on patients' lives and focus on setting specific goals which are relevant to patients' current values at the time such as reducing further hospital admissions (Bamford & Mountford, 2010).

Additionally as Colton and Pistrang (2004) suggest, there is a need for health professionals to support the positive aspects of peer relationships in treatment and to address the influence of negative behaviours. Increased monitoring of peer relationships in treatment and the discussion of peer influences within individual therapy sessions may allow patients to voice concerns and adopt appropriate coping strategies. Former inpatients in recovery could also be invited to share their experiences with current inpatients. This would allow inpatients to learn adaptive skills from a peer figure, while minimising the risk of negative influences. Some participants also expressed a desire for segregated living space from newly admitted patients while continuing to attend mixed group therapy sessions, to achieve periods of distance from those in distress and reduce the frequency of physical comparisons. However the feasibility of this remains unclear due to financial constraints of all services and the possible negative impact that it may have on the availability of peer support.

The current findings highlight that while inpatient treatment is perceived as essential for recovery, there remain existing challenges for patients regarding the transition to

and from inpatient treatment settings. Health professionals, particularly clinical psychologists can help prepare patients for inpatient treatment, facilitating the adjustment process. Clinicians can explore patients' expectations of treatment and discuss common thoughts and emotions often experienced throughout treatment. This may help to normalise distressed reactions particularly in the early weeks of treatment. Patients may find it useful to be given a detailed description of the treatment setting and structure prior to and during admission, to allow discussion of treatment expectations and possible challenges. It may also be helpful to provide advice on the different adaptive coping strategies other patients have used to adjust to the treatment environment in the past. The provision of such anticipatory guidance may help patients prepare for adjustment to treatment and address any feelings of a reduction in levels of perceived control. Increased opportunity for patients to engage in external social activities and to maintain relationships outside the inpatient setting may also help patients to feel connected with the outside world. Vanderlinden, Buis, Pieters and Probst (2007) argue that greater involvement of family members and peers are needed in the inpatient treatment of adult patients with AN to sustain progress. Clinical psychologists can provide educational information and training for patients' families to help them to assist with the rehabilitation programme when patients are on day or weekend passes home. This work may include how families manage short-visits home and how they can provide support consistent with the inpatient setting.

There is an identified need to focus on transitional care to help maintain patient recovery following discharge from inpatient settings. Previous research recommends the continuation of a supportive therapeutic relationship during the transitional phase

and allowing patients opportunities to make earlier connections with outside activities while in treatment to serve as an incentive to remain healthy when discharged (Offord *et al.*, 2006; Fennig *et al.*, 2002). In line with these recommendations, participants in the current study perceived opportunities to practise eating skills in external social settings and the increased focus of treatment on relapse prevention strategies as essential for coping with life post-discharge. This suggests the need to consider a planned graded decrease of intensity of professional support over time and the transfer of increased responsibility to the patient within the treatment environment. It may be helpful for inpatient treatment units to consider the implementation of social activities such as eating in restaurants or shopping in supermarkets that enable patients to practice their skills while remaining in the safety of treatment if problems arise. Clinical psychologists can also assess patients' emotional and psychological readiness for discharge and focus on relapse prevention work to actively address distress associated with discharge from the inpatient setting.

In relation to reports of inconsistencies between inpatient and outpatient services, patients would benefit from the designation of clear care pathways between services. The greater involvement of patients and professionals from outside agencies at review meetings and discharge planning meetings would enable clearer communication of the level of support required for the individual, particularly in the initial transitional phase. Clinical psychologists may play an important role in providing recommendations to outpatient services and organisations regarding the maintenance of a relapse prevention/chronic care programme following discharge. This would help to ensure a consistent working approach between services. The opportunity for patients to continue contact with inpatient services as day patients or the provision of

review meetings with a nominated member of staff may also facilitate continuity of care during the initial transition phase. However, in light of constrained budgets, the ability of all inpatient units to meet the demands of providing continuing support to those discharged while managing current and new patient admissions may prove challenging. Yet arguably, this may reduce the accumulative costs of repeated re-admissions considerably over time.

#### **5.4 Possibilities for future research**

The current findings relate to the treatment perceptions of one specialist adult inpatient unit explored using a qualitative design during a single time point in treatment. Future quantitative studies may wish to use published measures such as the Eating Disorder Patients Expectations and Experiences of Treatment Questionnaire (EDPEX) (Clinton, 2001) and the Questionnaire for Eating Problems and Treatment (De la Rie *et al.*, 2006) with patients with AN to evaluate treatment quality.

Participants' accounts also suggest a shift in perceptions over time, with their initial reactions to their treatment admission later developing into a sense of adjustment to the treatment environment and then fears of life following discharge. Future research may wish to explore the process of inpatient treatment using a longitudinal qualitative, quantitative or mixed qualitative-quantitative approach to identify how patients with AN experience treatment over time. It would be of particular value to carry out interviews or administer evaluative questionnaires at different time-points in treatment to identify any possible differences in views and experiences of treatment



over time. The administration of additional measures of eating psychopathology, motivation and mood ratings may also help to explore the relationship between stage of recovery and treatment perceptions.

It may also be useful to further explore the experiences of patients who have dropped out of treatment to identify factors which may contribute to treatment dissatisfaction. Given participants' negative experiences of outpatient services, it would be interesting for further qualitative studies to explore patients' perceptions of different treatment settings for AN including adult outpatient treatment and day-patient services. Additionally, the current study only focussed on the treatment perceptions of adult female patients with a diagnosis of AN, so future research may wish to explore the experiences of inpatient treatment from the perspectives of male patients or those with bulimia.

Narratives in the current study highlight difficulties accessing appropriate treatment, inequities in specialist service provision and challenges associated with service transitions. Current eating disorder research in this area remains limited and the experiences of patients with AN regarding these challenges have not yet been explicitly explored. It may be worthwhile to explore how patients experience treatment accessibility and the transitions between services. Such information would allow services to develop clearer integrated care pathways and further highlight the need for greater availability outpatient services.

In addition, an area for further quantitative or mixed quantitative-qualitative research might be to explore the role of the therapeutic relationship in treatment. While most

participants spoke of how the development of a supportive therapeutic relationship in treatment facilitated their treatment and recovery process, many continued to experience negative staff attitudes and behaviours. To date, there is dearth of research exploring the therapeutic alliance and treatment outcome in adults or adolescents with AN. It would be interesting to explore the association of treatment outcome scores with ratings of the therapeutic alliance and also therapists' characteristics. It may be worthwhile to explore the relationship between therapists' characteristics and the quality of the therapeutic alliance to determine what personal or professional characteristics positively influence the working alliance in treatment. In addition, there remains a need for further qualitative research into different health professionals' attitudes and experiences of aspects of treatment for eating disorders to identify specific training needs.

## **5.5 Methodological critique**

### **5.5.1 Strengths**

This is the first study to explore adult patients' experiences of specialist inpatient treatment for AN. Previous studies of patient perceptions of inpatient treatment for AN, have been based upon adolescent samples (Colton & Pistrang, 2004; Offord *et al.*, 2006; Van Ommen *et al.*, 2009), in relation to specific interventions (Griffiths *et al.*, 1996; Tan *et al.*, 2003; Whitney *et al.*, 2008) or in relation to general adult inpatient settings (Federici & Kaplan, 2008). Child and adolescent inpatient services and general inpatient settings may differ significantly from adult specialist inpatient units limiting the generalisability of previous findings to the experiences of adults receiving specialist treatment for AN. Additionally, three of these studies employed a retrospective design (Federici & Kaplan, 2008; Offord *et al.*, 2006; Van Ommen *et*

*al.*, 2009). Retrospective studies may have greater incidence of inaccurate information of experiences and perceptions due to recall bias and the current health and emotional status of former patients at the time of interview.

In the current study, patients were interviewed while actively receiving treatment, enabling a greater understanding into how adult inpatients experience their treatment, while reducing the risks associated with retrospective studies. Participants in the current study had a greater history of previous inpatient admissions than those in the previous adolescent studies, meaning that they had more experience of inpatients services and the availability of services following discharge. Their accounts were also characterised by comparisons between their current treatment admission and previous admissions to different inpatient services. This provided a more in-depth account of the overall experience of inpatient service provision for individuals with AN. These findings may help health professionals to develop a greater understanding of the treatment challenges facing adult inpatients and enhance current working practices to facilitate improved treatment adherence and outcome.

The current study adds to the understanding of the process of developing increased levels of perceived control during treatment, which is not explicitly highlighted in previous studies. This suggests that some adult service users may perceive a reduction in control as a positive step towards regaining greater personal control in their life. Similarly, unlike previous studies, participants in the current study highlighted a complex process of transition and adjustment to the treatment environment, providing a greater context to their fears of discharge. In addition, an important but tentative

finding from the current study is that participants experienced a growing sense of self-awareness and self-identity in treatment.

The current study adopted a qualitative approach to gain an in-depth description of treatment experiences, detailing the complex and often conflicting nature of accounts. It is likely that the complexities of patients' experiences would not have been captured by using quantitative methods alone. The study utilised theoretical sampling techniques by recruiting 21 participants across different treatment stages to gain an in-depth understanding of a possible wide range of treatment experiences. In addition, the researcher took a number of steps to enhance the methodological rigour of the current study including the utilisation of multiple reviewers to corroborate themes, respondent validation and a reflexive diary. The researcher also presented examples of quotations and summarised themes to provide further evidence of the analysis.

### **5.5.2 Limitations**

The current study has a number of methodological limitations. Participants were recruited from one specialist eating disorders inpatient unit within the independent sector, which provides treatment for patients with severe eating disorders. While the sample was homogenous in terms of gender (all female), demographic data of participants did not extend to the differentiation of sub-diagnoses of AN (i.e. restrictive versus purging subtypes). It remains unclear whether these findings are influenced by AN sub-diagnoses and/or if they are consistent with the treatment perceptions of male inpatients. Similarly, it is possible that the current findings may not reflect the treatment perceptions of patients with less severe anorexic symptoms.

Thus, the researcher acknowledges the need to apply caution in generalising the findings to other inpatient services.

The recruitment of participants was achieved through the assistance of staff within the unit, which may have resulted in possible selection bias. This may have meant only patients who staff felt would provide a favourable view were approached. In addition, the current findings are directly derived from information by participants with current eating psychopathology at different treatment stages. The researcher is aware of the possibility of participant accounts being influenced by their symptom severity and stage in treatment. Additional measures of psychiatric and eating disorder psychopathology were not undertaken. It was felt that the use of additional quantitative measures of symptoms could have limited participants' accounts. The development of the current study's inclusion/exclusion criteria ensured that only participants who were emotionally and physically able, were recruited and interviewed.

As most participants had a history of previous inpatient treatment for AN, there is a risk that participants described their previous treatment experiences during the interview. The researcher took several steps to focus participants' accounts on their experiences of their current treatment admission. The researcher explicitly used the terms "this inpatient treatment programme" to orient participants during the interview. The researcher sought clarification of whether participants' descriptions were of their current treatment admission or of previous admissions to either the same unit and/or different inpatient settings. Also, when participants discussed their

previous treatment experiences, the researcher enquired about how this compared with their current admission to refocus their accounts.

It can also be argued that participants' accounts may be influenced by the employment position held by the researcher, with participants possibly perceiving the researcher as a member of staff and feeling unable to discuss negative aspects of treatment. However, the rich description of both positive and negative treatment experiences suggests that this was not the case. The researcher also acknowledges the limited provision of information relating to the socio-economic status and cultural backgrounds of participants in the current study. It is possible that such information may influence particular views of treatment and would have allowed the researcher to reflect further on the findings in relation to this.

Additionally, the researcher acknowledges the possible impact of sequential analysis during the process of data collection and analysis in the current study. According to Miles and Huberman (1994), researchers may give "more weight" to participants' accounts which appear more articulate and omit data from participants who provide less descriptive or alternative accounts. Similarly, data collected earlier in a study may influence later interviews or the analysis of later transcripts (Miles & Huberman, 1994). This may lead researchers to seek further examples of already identified themes in later interviews rather than searching for new themes. In the current study, participants 1 to 4 were more descriptive in their experiences of treatment. These participants were also interviewed and had their transcripts analysed earlier in the research process, leading to the possible risk that their narratives influenced the analysis of later transcripts. The research undertook a number of steps to reduce this

risk of bias including searching for negative cases and reviewing earlier transcripts to identify examples of themes only identified in later transcripts.

## **5.6 Conclusion**

The current study has provided a greater insight into the lived experience of inpatient treatment for female adults with AN. The findings suggest that patients with AN experience inpatient treatment as challenging but necessary for recovery due to the provision of intensive support and supervision. Participants appear to experience a process of change and adjustment in relation to levels of perceived control, the treatment environment and a sense of self-identity. The findings suggest that treatment experiences may be influenced by the development of supportive relationships and effective responses to individual care needs.

**Title**

**Experiences of specialist inpatient treatment for anorexia nervosa**

**– A qualitative study from adult patients' perspectives**

**Abbreviated Title for Running Head**

**Experiences of specialist inpatient treatment**



## **ABSTRACT**

**Objective:** This qualitative study aimed to explore the lived experiences of adult female inpatients undergoing specialist inpatient treatment for anorexia nervosa.

**Methods:** Semi-structured interviews were carried out with 21 women (18-41 years) with a diagnosis of anorexia nervosa, undergoing treatment in a specialist adult inpatient eating disorder unit. Data were analysed using Interpretative Phenomenological Analysis (IPA).

**Results:** Qualitative analyses revealed 5 master themes: (1) shifts in control, (2) experience of transition, (3) importance of supportive staff relationships, (4) sharing with peers and (5) process of recovery and self-discovery.

**Discussion:** Findings suggest patients experience a process of change and adjustment in relation to levels of perceived personal control, attachment to the treatment environment and a sense of self-identify. Treatment experiences appear to be shaped by supportive relationships and individualised care.

**Keywords:** anorexia nervosa, inpatient treatment, qualitative research

**Abstract Word count: 129**

## INTRODUCTION

Anorexia Nervosa (AN) is a psychiatric condition with high co-morbidity and a mortality rate greater than any other psychiatric disorder (Nielson, 2001). Treatment for AN has traditionally been associated with poor treatment outcomes including poor weight maintenance and continued eating disorder psychopathology following discharge (Steinhausen, 2002; Pike, 1998). Treatment for AN also presents vast financial implications to healthcare services due to the need for long-term inpatient admissions to resolve medical complications and to restore the patient's weight within a normal range for their height and age. Growing financial constraints have led to increased instances of shortened inpatient treatment with patients being discharged at lower body weights (Wiseman, Sunday, Klapper, Harris & Halmi, 2001). However, research has found that inpatients with AN who were discharged at lower body weights were more likely to relapse and require re-admission (Baran, Weltzin & Kaye, 1995; Wiseman *et al.*, 2001).

In contrast, a recent longitudinal outcome study found that the eating and psychiatric pathology of adult patients with AN significantly improved following a specialist, multi-component and multi-disciplinary inpatient treatment programme (Collin, Power, Karatzias, Grierson & Yellowlees, 2010). As well as identifying the length of inpatient stay as a predictor of treatment outcome, the authors found high patient satisfaction in the sample with most aspects of the treatment programme (e.g. cognitive behavioural therapy, dietetic education, self-awareness work). However, the reliance on exclusively quantitative methods to explore patients' experiences of inpatient treatment components arguably limits the richness of information about how specific aspects of treatment influence treatment acceptance and outcome.

An additional approach to understanding how patients experience aspects of treatment is to explore the treatment experiences directly using qualitative methodologies (Colton & Pistrang, 2004). Qualitative research focussing exclusively on patients' experiences of inpatient treatment for AN is limited. A literature review of qualitative research published since 1990 revealed a small body of qualitative studies, which have explored patient experiences of treatment for eating disorders. The majority of published papers have focussed on the evaluation of outpatient and inpatient treatment for mixed eating disorder populations and not exclusively on treatment for AN (e.g. De la Rie, Noorenbos, Donker & Van Furth, 2006; Le Grange & Gelman, 1998; Reid, Burr, Williams & Hammersley, 2008). The use of mixed eating disorder samples is problematic, as differences in perceptions of treatment may exist between those with specific eating disorder diagnoses. However, fourteen studies were found to focus exclusively on patients' experiences of treatment for AN with seven of these studies describing patient perceptions of inpatient treatment programmes (Colton & Pistrang, 2004; Federici & Kaplan, 2008; Griffiths *et al.*, 1996; Offord, Turner & Cooper, 2006; Tan, Hope, Stewart & Fitzpatrick, 2003; Van Ommen, Meerwijk, Kars, Van Elberg & Van Meijel, 2009; Whitney, Easter, Tchanturia, 2008). Sample sizes in the seven studies ranged from 7 (Offord *et al.*, 2006) to 48 (Griffiths *et al.*, 1996).

In the previous studies of patient perceptions of inpatient treatment for AN, valued aspects of inpatient treatment included opportunities for patient collaboration and supportive therapeutic relationships (Colton & Pistrang, 2004; Offord *et al.*, 2006; Van Ommen *et al.*, 2009; Whitney *et al.*, 2008). Perceptions of opportunities for patient collaboration in treatment programmes enhanced treatment acceptance and satisfaction (Colton & Pistrang, 2004; Offord *et al.*, 2006; Van Ommen *et al.*, 2009).

In contrast, inflexible and compulsory interventions were seen as unhelpful (Griffiths *et al.*, 1996; Tan *et al.*, 2003). Therapeutic relationships which promoted a supportive, reliable and safe environment were also seen as important for patient satisfaction. In contrast, patients' perceptions of being labelled by some health professionals as "anorexics" rather than individuals led to treatment engagement difficulties (Colton & Pistrang, 2004; Offord *et al.*, 2006). Only two of the studies (Colton & Pistrang, 2004; Offord *et al.*, 2006) explicitly explored the influence of peer relationships within inpatient treatment. Patient perceptions of helpful aspects of receiving treatment alongside their inpatient peers included the provision of additional peer support which reduced feelings of isolation. In contrast, patient perceptions of unhelpful aspects included learning maladaptive behaviours and feelings of competition.

Previous research has also highlighted a need for increased provision of psychological interventions to address the emotional support needs of patients with AN (Colton & Pistrang, 2004; Federici & Kaplan, 2008; Offord *et al.*, 2006). In a study exploring relapse and recovery in prior inpatients with AN (Federici & Kaplan, 2008), relapsed participants perceived dietary aspects of inpatient treatment to overshadow opportunities to learn effective coping skills for discharge such as emotional regulation skills. This led to perceived difficulties at coping with emotional distress following discharge, negatively impacting their ability maintain their body weight. Furthermore, in a study of experiences of inpatient treatment and life following discharge (Offord *et al.*, 2006), patients felt removed from the daily activities of "normal" life in treatment, leading to difficulties with adjusting to life and maintaining progress post-discharge.

Although the findings of the previous studies highlight the complexity of inpatient treatment experiences for AN, the ability to generalise these findings to the experiences of adults receiving specialist inpatient treatment for AN remains unclear. Of the seven studies, three were based upon adolescent samples (Colton & Pistrang, 2004; Offord, *et al.*, 2006; Van Ommen *et al.*, 2009) and three in relation to specific treatment interventions such as compulsory bed rest (Griffiths *et al.*, 1996), compulsory treatment orders (Tan *et al.*, 2003) and cognitive training (Whitney *et al.*, 2008). The remaining study (Federici & Kaplan, 2008) focussed primarily on adult patients' views of their progress following discharge from a general inpatient treatment setting and not exclusively on their treatment experiences. In addition, only three studies recruited participants from specialist eating disorders treatment settings (Colton & Pistrang, 2004; Van Ommen *et al.*, 2009; Whitney *et al.*, 2008).

Furthermore, several of the studies were found to have methodological limitations. Firstly, most studies did not provide clear descriptions of the sample and the treatment programmes including the structure, delivery and content of treatment modalities. This lack of description makes it difficult to assess the patient and treatment variables that contribute to treatment perceptions. Secondly, three studies (Federici & Kaplan, 2008; Offord *et al.*, 2006; Van Ommen *et al.*, 2009) employed a retrospective design leading to a risk of recall inaccuracies.

Of the fourteen studies identified in the literature review, none of the studies have explored adult patients' experiences of specialist inpatient treatment for AN. To date, there remains a lack of detailed understanding of how adults with AN in inpatient specialist treatment programmes view aspects of their treatment. Given the variability of inpatient treatment outcomes in AN, a greater knowledge of how adult patients perceive inpatient treatment may help to improve current service provision

and reduce rates of relapse and re-admission. The current study aimed to add to the existing qualitative literature by being the first study of the authors' knowledge to explore adult female patients' experience of specialist inpatient treatment for AN during their treatment admission. These accounts provide an in-depth understanding of the key factors of the treatment experience, which health professionals working in adult inpatient settings may consider to facilitate the process of recovery and increase patient satisfaction.

## **METHOD**

### **Participants**

All female inpatients who met DSM-IV criteria (American Psychiatric Association, 1994) for AN as confirmed by psychiatric assessment upon admission and who were receiving specialist inpatient treatment were invited to participate in the study. Of 31 admissions occurring during the time of recruitment, 9 were ineligible to participate. Of those ineligible, three met DSM-IV criteria for bulimia nervosa, two were males, three had short-term admissions of less than ten days and one was considered by staff to be too medically unstable to be interviewed. One patient declined to participate in the study as she did not want to talk about her experiences. The remaining 21 patients agreed to participate in the current study

The 21 female participants ranged in age from 18 to 41 years ( $M = 25.2$  years;  $SD = 7.3$ ). The duration of anorexia according to patients' subjective reports ranged from 4 to 276 months from the onset ( $M = 76.1$ ;  $SD = 86.3$ ). The perceived duration of anorexia related to the time since initial diagnosis. The length of current treatment episode ranged from 2 to 28 weeks ( $M = 12.8$ ;  $SD = 8.5$ ). Eight (38.1 %) had no previous admissions and 13 (61.9 %) had received inpatient treatment on at least one previous occasion. All but one participant had voluntary treatment admissions. At the time of interview, participants' Body Mass Indices (BMIs) ranged from 11.8 to 21 ( $M = 16.6$ ;  $SD = 2.8$ ).

### **Inpatient treatment setting**

Participants were recruited from a 27 bedded specialist high intensity eating disorders unit, situated within the independent sector. The service has established referral pathways with NHS health-boards and independent healthcare organisations across

Scotland, providing inpatient treatment for adults with severe and enduring eating disorders. The inpatient treatment programme promotes a multidisciplinary treatment approach providing a combination of group therapies, individual counselling and dietetic management, which are personalised to individual support needs. The treatment programme incorporates a range of interventions, which are primarily cognitive behavioural in theoretical approach and focus on emotional regulation skills and the enhancement of self-esteem. These include anxiety management, cognitive behavioural therapy, behavioural activation, social skills training, positive psychology work and body image work. Dietetic aspects of the programme include meal supervision, nutritional education and eating skills groups which involve meal preparation work.

## **Procedure**

The recruitment procedure was devised in collaboration with clinical staff at the eating disorder unit. The researcher presented the study at a patient community meeting, which all patients attend as part of their treatment programme. Information sheets were distributed (in advance of the study) and patients were invited to participate by expressing interest through clinical staff.

The study was approved by the local area NHS Medical Research Ethics Committee and from the hospital director of the eating disorder unit. Written consent for participation in the study and the audio-taping of interviews was obtained from participants prior to the commencement of the interview. Participants were advised that their participation within the study was voluntary and that participation or non-participation would not affect their treatment. All interviews were recorded using a digital voice recorder and transcribed verbatim. Participants were issued with study



numbers in place of personal identifiers for the purpose of data collection, analysis and write-up.

Semi structured interviews were conducted to allow the researcher to ask specific open-ended questions while maintaining flexibility according to responses. Interviews were conducted in two phases over a period of 12 months. 13 interviews were carried out at the beginning of the year and 8 interviews were carried out over the later half of the year. There were no changes to the treatment regime during this time. Participants were interviewed individually and the length of interviews ranged from 15 to 60 minutes, with a mean duration of 36.9 minutes (SD=11.9).

The interview schedule was developed following a review of the existing eating disorders literature on treatment perceptions, with topic areas based on previous adolescent studies (Colton & Pistrang, 2004; Offord *et al.*, 2006; Tierney, 2008). Each interview initially focused on personal experiences of having anorexia to orient participants to the research area and to elicit information concerning their views of their recovery process. The second aspect of the interview probed key factors of the treatment experience including helpful/unhelpful aspects of treatment, living with other patients with eating disorders and suggestions for improving inpatient care. The final aspect of the interview gave participants an opportunity to provide further additional information at the end of the interview and explored their experiences of the interview. Responses were followed up with non-directive prompts such as by asking for information (e.g. can you tell me more?) or clarification of a specific examples (e.g. what would be an example of that?). Additional clinical information such as current Body Mass Index (BMI) was gained from clinical notes. A pilot interview was carried out, however no amendments were recommended.

## **Data analysis**

Interpretative phenomenological analysis (IPA) was utilised to analyse the transcripts (Smith & Osborn, 2003). IPA is concerned with the study of lived experience and focuses on the interpretation of personal sense making of a shared significant experience (Smith, Flowers & Larkin, 2009). Based on the guidelines provided by Smith *et al* (2009), the first author repeatedly re-read transcripts and used exploratory coding to note initial information of interest. Next, emergent themes were developed through the exploration of patterns of description within the initial notes. In the third stage, connections were made between emergent themes to produce higher level, super-ordinate themes to describe or label clusters of similar themes. This stage was facilitated using NVivo 8 (QSR, 2008), which allowed the researcher to organise the themes for each participant. In the final stage, recurring super-ordinate themes were identified across the group. Themes were classified as recurrent if they were present in a third or more of the participant interviews. Recurring super-ordinate themes were manually integrated into a table of master themes for the group, which reflected the structure of the data. Validity checks were conducted throughout the study to check the consistency of the themes with individual transcripts.

As recommended by Yardley (2008), a number of methods were utilised to strengthen the rigour of the study. The first author conducted the analysis and transcripts were reviewed by two independent reviewers. The first author was also part of a qualitative research supervision group and distributed coded samples within the group for review. Discussions facilitated refined interpretations, allowing the identification of new themes and re-structuring of the data set. The first author also sought respondent validation to assess whether the findings accurately represented participants views. The first author met with a different group of four female

inpatients with AN who were undergoing treatment within the inpatient unit, to elicit patient views on the findings. All four inpatients felt the themes fully represented their experiences of the inpatient treatment programme. Summaries of the findings were also sent out to the original participants who had all been discharged during the research process. In addition, the first author kept a reflective diary throughout the study to maintain a reflexive stance throughout the research process.

## RESULTS

Analysis revealed five master themes, which reflected participants' shared experiences of adult inpatient treatment. Table 1 shows an overview and description of the master themes and related sub-ordinate themes. Each master theme and its sub-ordinate themes (indicated using italics) are presented in turn with extracts from participant transcripts. Following this, hypothesised relationships between the themes are discussed to reflect the overall treatment experience. The extracts were selected because they provide the most coherent expression of the themes, while representing the views of the larger sample. Participants' names are replaced with a number to protect anonymity.

**Table 1.** Overview of master themes and sub-ordinate themes

<b>Master Themes</b>	<b>Sub-ordinate themes</b>
<i>1. Shifts in control</i>	1.1 Handing over of control of eating behaviours 1.2 Living within the restrictive environment 1.3 Regaining control 1.4 Seeking greater collaboration in treatment
<i>2. Experience of transition</i>	2.1 At the start I didn't want to be here 2.2 Treatment as a safe environment 2.3 Loss of normality: inside the safety bubble 2.4 Back to reality: concerns about loss of support and fear of relapse
<i>3. The importance of supportive staff relationships</i>	3.1 Importance of trust and making connections 3.2 Importance of being seen as a whole person not a walking eating disorder 3.3 Perceived inconsistencies in staff support
<i>4. Sharing with peers</i>	4.1 I am not alone – benefits of peer support 4.2 Learning from peers 4.3 Envy of emaciated peers 4.4 Coping with others' distress
<i>5. Process of recovery and self discovery</i>	5.1 Recovery as an arduous process: contrast between physical restoration and AN recovery 5.2 Role of self-motivation 5.3 Self-discovery and regaining confidence

## **Theme 1 - Shifts in control**

Most participants spoke of experiencing changes in their perceived levels of personal control throughout their treatment.

### *Handing over of control of eating behaviours*

Several participants talked about their preoccupation with their eating behaviours prior to treatment, highlighting a deterioration of perceived personal control over their eating disorder. The “handing over” of all perceived control within treatment was viewed as necessary for recovery, providing a sense of relief from the responsibility of ritualised routines. Some participants felt that the transfer of control of their eating behaviours to staff was an interim step towards recovery and regaining control.

*“...we get all meals in here and there is no option to have them or not, you must have them. The decision has been taken away from you almost and definitely if I hadn't been an inpatient I wouldn't have been able to eat” (Participant 5).*

*“...you don't have to think about, you don't have to control it anymore and you can give over that control...it just feels as if you are in that stage where you can't make any decisions and you are completely in a rut so it is nice to have other people take over” (Participant 17).*

Some participants felt anxious at handing over the level of perceived personal control that their eating disorder provided. The loss of perceived control in treatment was viewed as threatening to the self, leaving them feeling vulnerable.

*“...an eating disorder gives you a level of control and I was in control of me...it was very, very scary thinking if I come into treatment I have to hand over all control the eating disorder gave me. That made me feel very unsafe, insecure, very vulnerable” (Participant 3).*

### *Living within a restrictive environment*

Most accounts were characterised by conflicting views of the structured treatment environment. Participants described their dislike of the restrictive treatment environment. However, they felt the restrictive environment provided stability and purpose, removing opportunities to engage in their eating disorder behaviours.

*“...it is very restrictive and you hate that at first at how restrictive it is. There are no walks at first and your movement is limited and you watched constantly but it is needed, it really is needed.” (Participant 1).*

One participant felt that the provision of too much choice in a previous inpatient admission to another hospital had exacerbated her eating difficulties. In comparison, the structure of the current treatment programme enabled her to challenge her fear of the consequences of losing personal control.

*“When I was staying in another hospital I got worse in there because I was given too much choice...Here it is more structured ...sometimes getting your choice taken away is better. It’s all about control and we don’t have it and it shows you it is not all bad” (Participant 16).*

### *Regaining control*

Several participants described the process of regaining a “normal” level of perceived personal control over their eating during treatment. Participants initially questioned their ability to cope without the influence of their eating disorder. However, the gradual reduction of treatment restrictions and the experience of making choices that were not governed by their eating disorder resulted in feelings of empowerment.

*“...you think can I cope, can I manage but then as you actually do manage and cope without using eating disorder behaviours it is so empowering and you think I can actually do this... I can take a normalised control over my well-being and it is me in charge here...it is my choice...”(Participant 3).*

### **Seeking greater collaboration in treatment**

Several participants spoke of their wish to become more involved in treatment, perceiving limited opportunities to attend review meetings. This led to feelings of anxiety and frustration.

*“...maybe he could have spoken to me and said why it is not a good idea instead you just get an answer and you are like wait a minute and listen to me here...even if you do not agree with what they say, you would know why” (Participant 15).*

*“...sometimes I feel I am out of the loop and everyone knows what is going on and I find that it makes me feel really anxious because this is me and I am in the middle of it all and everyone is deciding what is happening and nobody is asking me” (Participant 18).*

Greater patient involvement in treatment was viewed as essential to improve treatment satisfaction. Most felt that having time to discuss treatment plans would facilitate patient understanding and acceptance of treatment recommendations.

## **Theme 2 - Experience of transition**

For the majority of participants, their experiences of being an inpatient involved coping with the differences between their home and treatment environments.

### ***At the start I didn't want to be here***

Most participants described their early difficulties in trying to adjust to the structured treatment environment and their separation from support networks at home. The early

weeks of treatment were a time of emotional distress for participants, even for those who had prior experiences of inpatient treatment.

*“...I was scared because I hadn’t been away from home...I was really nervous about it and at the start I hated it and wanted to get home” (Participant 2).*

*“I had gone from a home, stress-free not having to deal with anything in life, you are just living with your illness... Then I came in here...Oh my goodness, I had a headache for the whole first week or 10 days or something because it was so much...” (Participant 11).*

### ***Treatment as a safe environment***

Most described a sense of attachment to the treatment environment over time as they adjusted to inpatient life. Inpatient treatment was viewed as “safe”, offering protection from life stressors and providing a sense of familiarity. Several participants described inpatient treatment as “life-saving” due to the provision of intensive support, which was rarely provided in outpatient services.

*“...I have found it really helpful... it is a safe environment... You know you are surrounded by people who think can care 24/7 so you immediately feel safer than where you are at more risk” (Participant 17).*

For some, their growing dependency on the treatment programme and environment resulted in feelings of unease at the eventual prospect of discharge.

*“...the more you get used to things you start feeling comfortable and you become dependent on it... you feel it is your safe place almost. I kind of feel I am almost afraid to be here now because I have become quite attached to it and quite dependent on it” (Participant 6).*



***Loss of normality: inside the safety bubble***

Despite their attachment to the treatment programme, many participants spoke about feeling removed from a sense of “normal” life. While some participants felt that the removal from their home environment was necessary to allow them to solely focus on recovery, others felt that the treatment environment prevented practising their skills in everyday social settings.

*“...it can be a bit unreal in here as well because it is a bit of a safety bubble... You notice when you go out on pass is so much easier in here.... you do not have to eat your meals and no one is going to sit and make you eat” (Participant 4).*

Participants expressed a desire to re-connect with everyday life in treatment through the request of “normalising” social activities and the ability to practice behavioural skills outside the inpatient unit. This provided a sense of relief from feeling institutionalised.

*“...they took us to the pictures...a normal thing to do and it was ...nice to know there is life outside whereas when you’re in there 24/7 you can feel a bit like oh, you know” (Participant 18).*

***Back to reality: concerns about loss of support and fear of relapse***

Participants were aware of the initial difficulties in accessing specialist treatment and feared difficulties accessing appropriate outpatient support following discharge from the unit. Concerns regarding the reduction of support following discharge created feelings of unease at maintaining recovery in their home environment.

*“...you go from being an inpatient in here to going out and maybe seeing someone once a week...there is very little support out there...” (Participant 1).*

*“... I worry about going home full time because I am so scared and I hear this voice saying...it will be you and me again” (Participant 3).*

### **Theme 3 – Importance of supportive staff relationships**

Participants frequently discussed the development and quality of staff relationships in treatment and the impact these had on the treatment process.

#### *Importance of trust and making connections*

Most participants discussed the importance of building a trusting relationship with staff. Many described marked difficulties in their personal abilities to seek support in treatment. In light of this, supportive staff relationships were seen to facilitate help seeking behaviours, providing the confidence to disclose personal difficulties in treatment.

*“...you build up trust and you know who can say things to them and they understand a bit more because they know more about your past and where you have been...” (Participant 2).*

Poor connections with staff often resulted in feelings of distrust and the seeking of alternative means of support.

*“...when there’s a day where they are staff...you cannot find a connection with, it is hard if you’re having a bad day and I would pick up the phone before going to them...” (Participant 15).*

*The importance of being seen as a whole person not a walking eating disorder*

Participants valued individualised care, highlighting the need to be seen as an individual without the label of having an eating disorder. Participants felt it was important that staff provided a holistic approach in treatment, addressing both the underlying physical and psychological issues associated with their eating disorder. Opportunities to engage in individual counselling sessions were felt to be essential in treatment.

*“I think that one to ones we have with our therapists are very important because they help to tackle individuals’ problems rather than generally doing things. They really personalise it for you which I think is necessary” (Participant 5).*

Most participants spoke about valuing staff in the unit who adopted a person-centred approach. Staff interactions which made participants feel “normal” and less like a “patient” were valued.

*“... they do not treat you as if you have a problem. They are quite good at keeping you as an individual and they do like to get to know you without your eating disorder...” (Participant 1).*

In contrast, a few participants felt that some staff in the unit were unable to consider their individual preferences in treatment and treated all aspects of their behaviour as anorexic traits. The perceived inability of some staff to see beyond their eating disorder appeared to lead to a sense of frustration.

*“...it is always assumed that every single thing we say is an eating disorder. Yes sometimes it is but people genuinely do have likes*

*and dislikes...sometimes the gauge doesn't not seem to be there"*  
(Participant 11).

### ***Perceived inconsistencies in staff support***

While some participants felt supported by staff on the unit, others were less positive. Some participants felt that their treatment was complicated by staff support inconsistencies. While acknowledging the extent of staff responsibilities in the unit, participants at times felt overlooked, particularly in comparison to newly admitted patients.

*"...sometimes you are needing to speak to somebody and you cant speak to them... they have to see the new admissions before they see anybody but I have issues as well..."*(Participant 2).

*"Sometimes I feel I am not supported and sometimes I feel I'm getting loads of support...It depends who is on and how much staff is on so it varies"* (Participant 14).

Some participants felt certain staff members were insensitive towards their difficulties. Perceptions of negative staff attitudes appeared to increase feelings of anxiety, negatively impacting on treatment progress.

*"...if you have someone you are not comfortable with or you know they are quite snappy with you then you become paranoid and if there is food and you are struggling and you are worried they're going to shout at you that makes you struggle more"* (Participant 12).

### **Theme 4 - Sharing with peers**

Participants described their experiences of living with other patients who were also receiving treatment for AN and other eating disorders.

*I am not alone – benefits of peer support*

On reflection to their life prior to admission, most participants felt misunderstood and socially isolated due to their eating disorder behaviours. In contrast, participants described feeling understood and accepted by their peers in the treatment programme. Participants experienced a shared understanding by their peers above that found in relationships with staff.

*“...everybody here knows that we are all going through the same problems so nobody is looking at you or judging you...they know exactly what you are going through and at the same time if you do not want to talk about it...it is just almost understood”(Participant 17)*

*Learning from peers*

Participants frequently spoke of their positive experiences of learning from the experiences of their peers. This led to an increased knowledge of effective coping skills and a sense of hope for recovery.

*“... it is really good in terms of being able to hear how other people have gotten over, how they have gotten over the drive to exercise and how they have managed to eat certain foods. How did they cope with it and what did they do?” (Participant 3)*

In contrast, living with their peers made some participants more aware of and susceptible to adopting other unhelpful behaviours.

*“The most unhelpful thing is that you are with other peoples’ eating disorders definitely...people can be like do this and do that and when you come in and say pick that because it is safe...”(Participant 2).*

### *Envy of emaciated peers*

Sharing with peers also led to physical and behavioural comparisons, particularly with newly admitted patients. Participants frequently compared their physical appearance and eating behaviours with other inpatients in the treatment programme, acknowledging fears at being seen as “greedy” or overweight. This often resulted in feelings of inadequacy, guilt at recovery and a desire for further weight loss. One participant in her first admission described feelings of failure and the desire to relapse in order to become more deserving of treatment than her peers who had prior admissions.

*“It is hard for people when they come in and saying I was in before...it is like they are bragging... It makes you feel although I haven't been in before maybe that means I am not such as bad anorexic and I need to go home and start relapsing...”*  
(Participant 14).

### *Coping with others' distress*

Some participants spoke about the difficulties of living alongside peers who were unmotivated or distressed during treatment. For example, some participants reported witnessing episodes of self-harm. Participants perceived a responsibility to support distressed peers, which they felt disrupted their treatment focus.

*“Everybody has their own problems, they are all exploding at some point...it is something I feel I do not have to be dealing with. I would rather be focussing on my treatment in a more stable environment...”*  
(Participant 15).

## **Theme 5 – Process of recovery and self-discovery**

In the final master theme, participants spoke of their experiences of the recovery process and their growing sense of self-awareness as treatment progressed.

### *Recovery as an arduous process: contrast between physical restoration and AN recovery*

Most participants discussed their feelings in relation to their current stage of recovery from their eating disorder in treatment. The recovery process was characterised by a physical and emotional struggle to overcome their eating disorder.

*“Just the upset. You are fighting the eating disorder and having to put up with increases in your menu plan and you are constantly full. Me, I feel sick and constipated, feel tired and your emotions are everywhere...” (Participant 4).*

There was a strong suggestion that recovery would require the continuous awareness and management of residual symptoms beyond treatment. While most participants were regaining weight, they continued to experience and challenge maladaptive beliefs about their eating, weight and shape.

*“...each time I eat I then have to deal with the thoughts... That is still about but to a much lesser extent...So the thoughts are still there but I am not acting upon them...” (Participant 3).*

*“I am still struggling and it is hard...I want to get better and I still have the negative thoughts... It has been slow but it is still difficult. I still struggle” (Participant 19).*

### *Role of self-motivation*

While identifying the value of establishing supportive relationships in treatment, some participants also spoke of the importance of self-motivation. Participants strongly asserted that self-motivation was necessary for treatment acceptance and recovery.

*“...I am ready to change this time and unless you are ready to change I do not think it can work.” (Participant 4).*

### *Self-discovery and regaining confidence*

Some participants described a growing awareness of a sense of self throughout treatment. References were made to the process of separating themselves from their eating disorder and re-discovering their self-identity. This led to increased feelings of self-awareness and self-confidence.

*“...I find it difficult to distinguish... what is me and what is the eating disorder...a lot of what my treatment has been this time is actually...finding my own identity separate from the eating disorder” (Participant 3, interviewed at 20 weeks).*

*“...I am getting character in myself again and finding a personality and it is all coming back to me who I want to be...”  
(Participant 15)*



## DISCUSSION

The current study expands on previous qualitative literature by providing a detailed description of the experiences of specialist inpatient treatment for adult females with AN. Participants' narratives highlighted positive experiences and challenges in relation to coping with a sense of "change" throughout the treatment process. Analysis of accounts revealed five master themes; "Shifts in Control", "Experience of Transition", "Importance of Supportive Staff Relationships", "Sharing with Peers" and the "Process of Recovery and Self-discovery".

Consistent with earlier work (e.g. Offord *et al.*, 2006), participants' narratives suggest a change in levels of perceived personal control when entering inpatient treatment. While some participants felt relief at handing over personal control seeing this as an active step towards recovery, others felt increasingly vulnerable. The way in which patients experience the change in levels of perceived personal control during inpatient treatment may have a direct impact on their coping ability. This finding that individuals with AN feel threatened by a reduction in perceived control, may explain why some patients cannot tolerate treatment restrictions (Sternheim, Konstantellou, Startup & Schmidt, 2010). Some participants felt their levels of perceived personal control increased as treatment progressed, leading to feelings of self-competency, a finding which was not explicitly highlighted in Offord *et al.*'s (2006) earlier study. Similar to previous adolescent studies (Colton & Pistrang, 2004; Offord *et al.*, 2006), some participants spoke about having limited opportunities for collaboration in their treatment, which resulted in feelings of frustration and reduced levels of perceived control.

Participants experienced a process of transition between their home and treatment environments. Unlike previous studies, some participants expressed a sense

of attachment to the treatment environment over time. Inpatient treatment was perceived to offer protection from everyday stressors, providing intensive support. However, as in Offord *et al* (2006) participants also felt removed from aspects of “normal life” in treatment resulting in a longing for normalising social activities. Participants were concerned about their abilities to maintain their recovery within their home environments following discharge. The challenges of the transition home have led to comparisons with “separation-individuation” stages of child development, associating repeated admissions with poor emotional readiness for discharge (Fennig, Fennig & Roe, 2002; Vandereycken, 2003). It has also been recognised that patients with eating disorders experience difficulties accessing appropriate care due to the regional inequities of specialist outpatient services (Escobar-Koch *et al.*, 2010). As highlighted with adolescent services, planned transitions of care between services were viewed by patients as essential to reduce concerns of loss of support following discharge (Arcelus, Bouman & Morgan, 2008).

Consistent with previous research, participants’ accounts focused on *how* treatment was delivered rather than the treatment content (Bell, 2003; Espindola & Blay, 2009). Participants explicitly valued trusting and supportive staff relationships, which enabled disclosure of personal difficulties. In contrast, participants experienced a sense of frustration at staff who they felt perceived as failing to recognise their individual preferences. Staff difficulties at determining the differences between individual preferences and anorexic behaviours have been highlighted in previous adolescent studies (Colton and Pistrang, 2004; Offord, *et al.*, 2006). Also, participants valued the holistic nature of the treatment programme, describing the importance of receiving dietetic and psychological interventions. Recent research has noted increased patient satisfaction with treatment which incorporated a multi-treatment

approach (e.g. Button & Warren, 2001; Colton & Pistrang, 2004; Federici & Kaplan, 2008).

Conflicting experiences of patient peer support have been previously highlighted in the adolescent literature (Colton & Pistrang, 2004; Offord *et al.*, 2006; Tierney, 2008). The current study suggests that similar experiences of peer support occur within adult inpatient services. Participants at times perceived peer support as more helpful than professional support. Sharing of experiences provided knowledge of coping skills and hope for recovery. In contrast, some participants also experienced increased self-comparison and distress. Comparisons with the physical appearance and behaviours of their peers strengthened their existing eating disorder beliefs and led to an awareness of new eating disorder behaviours. In the current study, negative experiences were particularly associated with the arrival of newly admitted patients, who served as reminder of their previous anorexic state.

Consistent with previous research, participants experienced the recovery process as a continuous struggle (e.g. D'Abundo & Chally, 2004; Federici & Kaplan, 2008; Granek, 2007). However, in the current study, a desire to pursue life goals such as returning home to children resulted in an increased motivation to get well. In addition, a finding from the current study is that participants perceived an increased sense of self-identity in treatment, which was not characterised by their anorectic behaviours. The acquisition of an alternative sense of identity through anorexia, replacing an individual's own "fragile" self-identity has been previously highlighted (Espindola & Blay, 2009; Norbo, Espeset, Gulliksen, Skarderud & Holte, 2006). Thus, it may be that inpatient treatment strengthens self-identity, allowing separation from the "anorexic" identity and facilitating recovery.

These findings have a number of treatment implications. There is a recognised need for improvements in health professional training in eating disorders (NHS QIS, 2006; NICE, 2004; Reid, Williams & Burr, 2010). Consistent with previous research, treatment experiences were influenced by the quality of staff interactions with emphasis placed on therapist characteristics which promoted a supportive environment (Fuertes *et al.*, 2009; Kaplan & Garfinkel, 1999; Mostow *et al.*, 2010; Vanderlinden, 2007). However, the value of non-specific therapeutic skills can often be underestimated in treatment, suggesting the need for health professionals to reconsider the use of relational models in clinical practice to facilitate a strong therapeutic alliance. Bamford and Mountford (2010) suggest that therapists should focus primarily on engagement and providing consistent support. Recent therapeutic programmes have been developed for health professionals working with patients with AN, which focus on developing a supportive therapeutic context in treatment to increase treatment adherence (Bamford & Mountford, 2010; McIntosh *et al.*, 2006). Clinical psychologists have extensive training in core therapeutic skills and are in a key position to provide training and supervision on building a strong therapeutic alliance to professionals working with patients with eating disorders.

Individualised, person-centred approaches providing opportunities for greater patient collaboration may help to improve patient satisfaction (Colton & Pistrang, 2004; Espindola & Blay, 2009; Offord *et al.*, 2006). Clinical psychologists can provide advice or work alongside other staff to develop case formulations in collaboration with each patient to encourage an individualised and collaborative treatment plan (Lavender & Schmidt, 2006). The findings also suggest there is a need for greater access to psychological therapies, which focus on improving quality of life and are tailored to patients' support needs. The current study highlights the difficulties

of achieving psychological recovery from AN during treatment. This suggests the need for clinicians to look to models of recovery in which individuals are supported to achieve improvements in their quality of life even in the presence of chronic symptoms (Brown & Kandirikirira, 2007). Bamford and Mountford (2010) suggest that therapeutic interventions for individuals with severe and enduring AN should specifically focus on psychological rehabilitation strategies such as skills training, goal planning and motivational enhancement to increase appropriate coping skills for discharge. As identified in previous research (Bamford & Mountford, 2010; Treasure & Schmidt, 2001) there is a need for clinicians to focus motivational work on achieving goals which are relevant to patients' current values at the time such as reducing further hospital admissions. There is also a need for health professionals to address peer relationships in treatment (Colton & Pistrang, 2004). Increased monitoring and discussion of peer relationships in treatment may allow patients to adopt appropriate coping strategies. Former inpatients in recovery could be invited to share their experiences with current inpatients. This would allow inpatients to learn adaptive skills from a peer figure, while minimising the risk of negative influences.

The findings highlight difficulties associated with the transition between the home and inpatient treatment environments. The provision of anticipatory information at admission and increased opportunities for patients to engage in appropriate social activities while in treatment may also facilitate adjustment to the treatment environment. In addition, Vanderlinden, Buis, Pieters and Probst (2007) argue that greater involvement of family members is needed in the inpatient treatment of patients with AN. Clinical psychologists can provide educational information and training for patients' families to help them to assist with the rehabilitation programme when

patients are visiting home. This work may include how families can provide support consistent with the inpatient setting.

In addition, earlier discharge planning with patients and relevant outpatient support services would enable clearer communication of the level of support required and help to reduce patient concerns about support inconsistencies. The findings highlight a need to consider a planned graded decrease of intensity of professional support over time and the transfer of increased responsibility to the patient to prepare for discharge. Psychological rehabilitation strategies such as skills training and relapse prevention work may increase patient confidence and reduce distress associated with discharge from the inpatient setting. The opportunity for patients to continue contact with inpatient services as day patients or the provision of review meetings with a nominated member of staff may also facilitate continuity of care during the initial transition phase.

Future longitudinal qualitative research is needed to explore how patients with AN experience treatment at different points in time. Narratives in the current study highlight difficulties accessing appropriate treatment, inequities in specialist service provision and challenges associated with service transitions. Current eating disorder research in this area remains limited. Further quantitative and qualitative research is also needed to explore the contribution of therapist characteristics in relation to treatment adherence and outcome in patients with AN.

The current study has a number of methodological strengths and limitations. This is the first study to explore adult patients' experiences of inpatient treatment for AN. Participants were interviewed while actively within treatment, providing reports of current treatment experiences. The number of participants interviewed consisted of a high proportion of those within the inpatient setting who were eligible to participate

in the study, suggesting that the views of the selected sample were fully represented. Validity checks of the findings were carried out with additional researchers and patients. Among its limitations are that participants were recruited from one specialist inpatient unit in the U.K. While some demographic and clinical data is presented, this did not extend to the differentiation of sub-diagnoses of AN (i.e. restrictive versus purging subtypes) and personal variables such as socioeconomic status. Staff in the unit assisted with recruitment, which might have led to the inclusion of patients who would provide only positive reports. The current project reduced the potential for recall bias by conducting interviews during the inpatient admission. However other factors influencing participants' perceptions of treatment may include stage of recovery and anxiety about disclosing dissatisfaction with ongoing treatment.

In conclusion, the current study is the first to provide a detailed description of the lived experiences of a specialist inpatient treatment programme for women with AN. The results of the study suggest that patients experience a process of change and adjustment in relation to levels of perceived personal control, attachment to the treatment environment and a sense of self-identify. The ability to cope with these perceived changes, appear to be influenced by the development of supportive relationships and individualised care.

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## APPENDICES

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**APPENDIX 1**

**Letter of NHS Tayside Ethics Committee approval**



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**Fife, Forth Valley & Tayside Research Ethics Service**

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**Tayside Committee on Medical Research Ethics A**

Research Ethics Office  
Level 9  
Ninewells Hospital & Medical School  
DUNDEE  
DD1 9SY

Ms Vivien Smith  
Trainee Clinical Psychologist  
University of Edinburgh  
Eating Disorders Service  
55 Constitution Road  
Dundee  
DD1 1LB

Date: 24 December 2008  
Your Ref:  
Our Ref: LR/DL/08/S1401/112  
Enquiries to: Miss Lorraine Reilly  
Extension: Ninewells extension 40099  
Direct Line: 01382 740099  
Email: [Lorraine.reilly@nhs.net](mailto:Lorraine.reilly@nhs.net)

Dear Ms Smith

**Full title of study:** Adult Inpatient Treatment for Anorexia Nervosa: A Qualitative Study of Patient Experience  
**REC reference number:** 08/S1401/112

Thank you for your letter of 25 November 2008, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

**Ethical review of research sites**

The Committee has agreed that site-specific assessment is not required for the following site(s):

Research site	Name of PI (CTIMPs only) or local contact point	Post
*****	*****	Hospital Director

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Response to Request for Further Information		25 November 2008
Participant Consent Form	2	25 November 2008
Participant Information Sheet	2	25 November 2008
Letter from EDU, confirming written permission to recruit patients for research project		20 August 2008
Letter from University of Edinburgh - student confirmation		20 August 2008
Letter from AON - statement of indemnity arrangements - renewal date: 01/08/2008		20 August 2008
Participant Debrief Information Sheet	1	30 September 2008
Summary CV for supervisor (student research)		30 September 2008
Interview Schedules/Topic Guides	1	30 September 2008
Letter from Sponsor		02 October 2008
Covering Letter		30 September 2008
Protocol	1	30 September 2008
Investigator CV		
Application	1	24 September 2008

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review.

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures. We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk)

<b>08/S1401/112</b>
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<b>Please quote this number on all correspondence</b>
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Yours sincerely

**Dr. Carlos Wigderowitz**  
**Chair**

Enclosures: “After ethical review – guidance for researchers”,

Copy to: Ms Elspeth Currie, Edinburgh Clinical Trials Unit

**APPENDIX 2**

**Letter of hospital approval**



Our Reference: DG/EM

20<sup>th</sup> August 2008

**To Whom It May Concern**

Dear Sir/Madam

Re: “Adult Inpatient Treatment for Anorexia Nervosa: A qualitative study of patient experience” by **Vivien Smith, Trainee Clinical Psychologist, Eating Disorders Service, Constitution House, Dundee**

I am delighted to confirm written permission on behalf of \*\*\*\*\*, that Vivien will have access to the population required for the above named study. In particular, she will have access to at least 20 female service users diagnosed with and treated for eating disorders aged 16 and over.

In addition, she will enjoy the full collaboration with management and the clinical team whilst undertaking this project.

I trust that this will meet with your requirements.

Please let me know if you require further information.

Kind regards.

Yours sincerely

A handwritten signature in dark ink, appearing to read 'D. G. Smith', written in a cursive style.

**HOSPITAL DIRECTOR**

**APPENDIX 3**

**Participant Information Sheet**



## **Patient Information Sheet**

### **Title of Project: Adult Female Inpatient Treatment for Anorexia Nervosa: A qualitative study of patient experience.**

You are being invited to take part in a research study that is being conducted in part fulfilment of Doctorate in Clinical Psychology degree at the University of Edinburgh. Before you take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please contact the lead researcher (Vivien Smith, Trainee Clinical Psychologist), if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part.

#### ***What is the purpose of the study?***

The aim of the study to help us understand the experiences of people within inpatient settings who have eating difficulties. People with eating difficulties often have to spend some time within specialist eating disorders inpatient settings. It seems that their personal experiences of this type of treatment have often not been evaluated. In this study I would like to ask about your experiences of your eating difficulties and your current inpatient treatment.

#### ***Why have I been chosen?***

Individuals included in this study will be:

Females with a diagnosis of Anorexia Nervosa, who are aged 18 or older.

#### ***Do I have to take part?***

No. Your participation in the study will be voluntary and your responses will remain anonymous. If you do decide to take part you will be given this information sheet to read carefully and then asked to sign a consent form. If you decide to take part **you are still free to withdraw at any time and without giving a reason.** If you withdraw, your data will be destroyed. A decision to withdraw at any time will not interfere in any way with your treatment or care. A decision to take or not take part in this study will not affect your treatment and care or your relationship with staff in any way.

#### ***What will happen to me if I take part? What do I have to do?***

If you do decide to take part, you will need to sign a consent form to make sure that you have understood the information on the form.

You will be asked part in one interview about your personal experiences. The purpose of such questions is to find out more about the experiences of women being treated for

eating difficulties. This interview is expected to last approximately 40-60 minutes and will take place in a quiet room at the \*\*\*\*\* (or your own room at the \*\*\*\*\*). I would like to audiotape the interview for better recall and analysis of the information you provide. However, if you do not wish the interview to be audio taped, please let me know about your wishes and I will only keep notes. I will be happy to provide breaks at any point within the interview should you feel upset or tired. The information you provide will remain confidential unless you disclose a risk to yourself or another person. If a risk is indicated, clinical staff will need to be informed. You will be given a letter providing additional sources of support after the interview and contact details should you have any later questions. You will be provided with a written summary of the findings of this research and given the opportunity to discuss this with the lead researcher (Vivien Smith, Trainee Clinical Psychologist).

***What are the possible advantages/disadvantages of taking part?***

People who have taken part in similar studies have found it a positive experience to have a chance to feel listened to. However, you may find it upsetting if you decide to discuss any experiences that have been difficult for you. If you do feel upset I will be happy to stop the interview for a break or to reschedule. You may also decide at this point that you wish to withdraw from the study. Additional support will be available from the clinical team within the unit should you feel that you would benefit from an opportunity to discuss any issues further.

The information that we get from this study will help us better understand the views and needs of women who experience eating difficulties. This will not lead to immediate changes within the service, although we hope that the findings of the study will contribute positively to better treatment and care for people with such difficulties in the future. The results of the study are likely to be published so that its findings can be used across the United Kingdom, however you will not be identified in any report or publication.

***Will my information be kept confidential?***

Yes. All the information that is collected during the course of the study will be kept confidential. However, if information that is disclosed throughout the course of the interview indicates a risk to yourself or others then confidentiality would need to be breached and clinical staff informed.

In the study, your name will be replaced with a participant number, and it will not be possible for you to be identified in any reporting of the data gathered. All audio-recordings and transcripts will be kept in a locked cabinet within the \*\*\*\*\* Hospital property. Once the final report is written, all tapes and transcripts will be destroyed. The information you provide in the interview will not be shared by anyone outside the research team unless it indicates a risk to yourself or others. You will not be identified in any reporting of the data gathered.

The Tayside Committee on Medical Ethics A, which has the responsibility for scrutinising proposals for medical research on humans, has examined this proposal and has raised no objections from the point of view of medical ethics. The study has also been reviewed by appropriate groups of people in \*\*\*\*\* and University of Edinburgh. Sometimes in order to make sure researchers are doing what they said they would, it is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from NHS Tayside and the University of Edinburgh.

***What will happen to the results of the study?***

The results of the study will be submitted to Edinburgh University for review and may be published in a report, scientific journal and/or presented in conferences. Direct quotes from interviews will only be used after being anonymised and any information that might identify you will be removed.

***What if there is a problem?***

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you decide to take part in the research and are not happy with any aspect of the study, you should ask to speak to the lead researcher, Vivien Smith (01382 424534) or the clinical liaison for the study, Dr \*\*\*\*\*, Medical Director, \*\*\*\*\* Hospital. Further contact details are given at the back of this sheet. In the event that you are harmed during the research and this is due to someone's negligence then you may have grounds for compensation but you may have to pay your legal costs.

***What to do next?***

If you are willing to take part in this study please arrange an interview meeting by booking yourself a slot in the interview schedule available (at the nurse station). At the meeting the interviewer (Vivien Smith, Trainee Clinical Psychologist) will ask you to complete the consent form before your interview takes place.

Thank you for taking the time to read and consider the above information.

***Contacts for further information***

Should you have any further questions about the study, please contact:

Name of Lead Researcher:	Ms Vivien Smith, Trainee Clinical Psychologist
Address	NHS Tayside Eating Disorders Service Constitution House 55 Constitution Road Dundee, DD1 1LB
Email / Telephone:	01382 424534

Name of supervisor

Address

Email / Telephone:

Should you have any concerns about your treatment or care, please contact:

Name of clinical liaison:

Address:

Email / Telephone:

Additional contact

Address:

Email / Telephone:

**Thank you for taking the time to read this information sheet**

**APPENDIX 4**

**Debriefing handout**



## **Participant Debrief Information Sheet**



Title of Project: Adult Female Inpatient Treatment for Anorexia Nervosa: A qualitative study of patient experience.

Name of Lead Researcher: Ms Vivien Smith, Trainee Clinical Psychologist

Dear Participant,

I would like to thank you for agreeing to participate in this research. Your help and contribution is very much appreciated.

If you would like to learn more about this study, please do not hesitate to contact me by email, at [viviensmith@nhs.net](mailto:viviensmith@nhs.net) or phone at 01382 424534. Alternatively, you may prefer to contact my supervisor \*\*\*\*\* by phone on \*\*\*\*\*..

This study is not intended to upset you in any way. However, the interview may have raised some issues or concerns. If you feel you need information, advice or support about some of the issues raised in this study and/or your interview, you should contact \*\*\*\*\*, named clinical liaison for the study at the \*\*\*\*\* Hospital.

For more information about health and eating difficulties, the following websites maybe useful:

<http://www.b-eat.co.uk/Home>  
<http://www.sedig.co.uk/>  
[www.healthscotland.com](http://www.healthscotland.com)

I would like to thank you for your time and consideration.

Yours sincerely

Vivien Smith  
Trainee Clinical Psychologist



**APPENDIX 5**

**Participant Consent Form**



Study number: 08/S1401/112  
Patient Identification Number for this trial:



## CONSENT FORM

Title of Project: Adult Female Inpatient Treatment for Anorexia Nervosa: A qualitative study of patient experience.

Name of Lead Researcher: Ms Vivien Smith, Trainee Clinical Psychologist

**Please initial box**

1. I confirm that I have read and understand the information sheet for the above study. I have had an opportunity to ask questions and these have been answered.

☐

2. I understand that my participation is voluntary and that I have the right to withdraw from the study at any stage without my medical care or rights being affected

☐

3. I agree to information being audio-taped and transcribed

☐

4. I understand that relevant sections of my medical notes and the data collected during the study may be looked at by individuals from the University of Edinburgh or from NHS Tayside, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

☐

5. I understand that small parts of my interview may be used for publication in reports. I understand that should this happen, I will not be identified from any of the information provided.

☐

6. I agree to participate in this study.

☐

_____ Name of Patient	_____ Signature	_____ Date
_____ Name of Interviewer	_____ Signature	_____ Date

**APPENDIX 6**

**Interview Schedule**

## **Interview Schedule**

Prior to interview, the Lead Researcher will go through the information sheet again with the participant and obtain informed consent.

### **Demographic information:**

Demographic information gathered prior to the main interview will include the following:

- Age
  - Length of time since diagnosis
  - Length of time since current admission
  - Number of prior admissions if any
- 

The following questions will be used to guide and facilitate a discourse between the Chief Investigator and each participant. Prompts will be used minimally to encourage further information from participants.

### **Experience of Eating Difficulties:**

1. Can you tell me in your own words, about your experiences of your eating difficulties?
  - (Prompt) has your eating difficulties impacted upon your life in any way?
  - (Prompt) if so, in what way?
  - (Prompt) how do you currently feel about your eating difficulties?

### **Experiences of Inpatient Treatment:**

2. Can you tell me about your experiences of this inpatient treatment programme for your eating difficulties?
  - (Prompt) how has it been for you undergoing this treatment programme?
  - (Prompt) can you tell me what you think about this treatment programme?
  - (Prompt) are there any aspects of this programme that you find helpful or unhelpful?
  - (Prompt) how do you feel about being with other people in the same situation as yourself?
  - (Prompt) is there anything you think would make your experience of this treatment programme better?

3. Is there anything that you would like to share, but did not have the chance in the previous questions?

4. How was the experience of this interview for you?

**Additional prompts:**

- I'm interested in...can you tell me more about that?
- What do you mean by that?
- What would be an example of that?
- What did you do?
- How do you feel about that?
- What do you think about that?
- What were your thoughts then?

**APPENDIX 7**

**Initial coding of transcript for Participant 3**

Thematic coding	Interview: Participant 3  (I = interviewer P = participant)	Exploratory codes  Coding: Underlined= description/content Italics= language Bold= conceptual/interrogative
<p>Loss/removal from normality</p> <p>Difficulty coping with restrictions</p>	<p><b>I:</b> Can you tell me about your experiences of your inpatient treatment for your eating difficulties?</p> <p><b>P:</b> it has been hard in terms of being away from family and friends. I guess family and friends are a big part of enabling me to be in recovery. I love them dearly and I do not want them to go through anymore upset than what they have had to go through. Coming into inpatient care again meant I was having to remove myself from my parents, my friends, close family members and that was hard. Having all the restrictions put on me was hard as well. Not being able to go out for any kind of walk initially, you are restricted in your movement considerably. You are only allowed to move around your ward or in your bedroom.</p> <p><b>I:</b> why is that?</p> <p><b>P:</b> again it is minimising the amount of activity you do so you are not burning energy and whatever nutrition you are taking in is staying and enabling you to gain weight. Also it is a health and safety issue as well because if you are moving about too much you could be risking breaking something, following over, depending on your physical health.</p> <p><b>I:</b> how did you feel about that?</p> <p><b>P:</b> it was horrendous, it was hard because I knew I was not going to carry out behaviours and being over active but I thought I would at least have some level of activity that would help minimise the drive. That didn't help the drive any but then what happened was I became terrified of any form of activity and I was so scared if I did</p>	<p><u>hard</u> <b>sense of separation</b></p> <p><u>remove myself from support/relationships/life?</u> <u>restrictions hard</u></p> <p><u>restricted activity</u></p> <p><u>minimising activity</u> <u>enabling weight gain</u></p> <p><u>horrendous</u> <u>hard to not be overactive</u></p> <p><u>terrified/scared of activity</u></p>



<p>Loss of control of eating</p>	<p>anything at all it would kick in the drive again. So I ended up even when I was allowed to go on walks, not go because I was too scared. That was a real hard part having such a... you had lost all control of what you ate and when you ate. You have a menu that is set for you and are required to eat that amount on a daily basis and you have signed a contract to comply with that menu plan and to comply with the treatment. So the dietician sets you with a menu plan and you have choice to a small extent in the evening meals there are always three choices. A meat, a vegetarian, and a fish dish say. You then have to choose between those three are not other options and that is set and you have to eat what comes on your plate. That is really hard because you have no control over your food and the amount and you go down and a chef is serving you up that food. You have no control over the portion size, how it is cooked, are the potatoes and vegetables tossed in butter, what oil has been added...</p>	<p><b>fear of activity restarting anorectic behaviours?</b> <b>Avoidance</b></p> <p><u>Lost all control of eating behaviours?</u></p> <p><u>contract to comply</u></p> <p><u>choice to a small extent</u></p> <p><u>you have to eat</u></p> <p><u>no control over food or amount</u></p>
<p>Removal of control is essential for recovery</p>	<p>I: what do you think about that process?</p> <p>P: Now I think that process is absolutely ideal and is essential. We have to have a certain level of nutritional intake in order to enable weight gain because I think the only way we can recover is to gain weight. I do not think anorexia or bulimia... I do not think an eating disorder is all about weight. But I think recovery requires weight gain and therefore the control being taken away from us with regards to the nutritional content of foods, amounts, the selections, I think it is essential. If we had our way there would be no fat in it and no calories. If we were given a choice if we ate it or not then it would take such a long time for us to get started on eating.</p> <p>I: you mention the word 'control' can you talk more about that feeling?</p> <p>P: yes, I think one thing you believe and I know I believe is an eating disorder gives you a level of control and I was in control of</p>	<p><i>Now – retrospective stance</i></p> <p><u>process ideal and essential</u></p> <p><u>weight gain necessary for recovery</u> <u>eating disorder not all about weight</u> <b><u>other things involved but weight gain part of recovery?</u></b></p> <p><u>control being taken away is essential</u> <b>choice would allow continuation of eating behaviours</b></p> <p><u>eating disorder provides self-control</u></p>

Handing over of control in treatment	me. Agreeing to come into inpatient treatment means you are definitely handing over all control whether it be your activity levels, foods, whatever. That is hard because you believe that the control the eating disorder gives you is actually what is keeping you safe. I know that sounds bizarre because it is actually hugely destructive and is killing you but I guess in a way I got to the stage I didn't care if that was the outcome, I needed that level of control over myself. I needed to be so disciplined over my food and needed to be so disciplined over my activity levels. It was very, very scary thinking if I come into treatment I have to hand over all that control the eating disorder gave me. That then made me feel very unsafe, insecure, very vulnerable.	<u>handing over all control</u>  <u>control keeps you safe</u>  <u>eating disorder</u> <u>destructive</u> <b>dependency on control</b> <u>-disciplined</u>  repeated use of <i>very</i> <u>scary</u> <u>handing over control in treatment</u> <u>unsafe, insecure,</u> <u>vulnerable</u>
Feeling unsafe at handing over control		
Change in control over time	<b>I:</b> how do you feel now?  <b>P:</b> again hopefully very different! I do not feel so scared about the ***** still having a level of control over me but I feel what I have been able to do over time was gain a level of control that is actually at a normalised level of control, it is not an eating disorder level of control. I have gained choice and again it is not about, the treatment does not mean you earn that control, it is not a reward punishment program or anything like that. As you progress in treatment and as you mentally and physically get better you gain trust in yourself and gain trust in the staff and they then gradually give you some of that control back. You get to do meal prep and that is where you are choosing a menu and you are cooking for yourself and it is all about you choosing a menu and preparing it all and following a recipe so it means you are adding fats to it and not counting calories. You are making a meal you are more in control of.	<b>sense of time</b> <b>change in perceptions over time?</b> <u>gaining level of control</u> <u>normalised level</u>  <u>gained choice</u>
Process of regaining control/ choice over time		<u>gain trust in self and staff</u> <u>handing back of control</u>  <u>choosing</u> <u>cooking for self</u> <b>sense of greater responsibility and freedom</b>
Reduction of restrictions over time	<b>I:</b> can you give me other examples of that kind of choice being gained?  <b>P:</b> where activity is concerned, you are allocated one 15 minute walk to start with	<u>more in control</u>

Learning to trust self	and then it goes up to two 15 minute walks and that is with staff. It then moves on to having 15 minute walks with other patients so you're out there are unsupervised so again you're gaining that little bit more control back because it becomes up to you and you go out and take that 15 minute walk and you decide whether you are walking it fast, normal pace, whether you stick to the route, or do 15 minute power-walking around a different route which is more strenuous or whatever. So very much it becomes your control as to how you manage yourself being active.	<u>building up of activity/lessening of restrictions</u>
Process of regaining greater personal control/choice	<b>I:</b> how does that feel gaining that more control?  <b>P:</b> it is scary at first because you have to gain trust in yourself as well. You are being given these new controls to yourself but part of you thinks oh my gosh can I actually manage having a normalised level of control or is it going to go back to an eating disorder level of control. That is what becomes scary because you then have to try and trust yourself that you can do it in a normalised fashion and you do not have to rely on eating disorder. Another example would be initially when you come in you are put on table supervision. So you eat your meal under the supervision of staff members and are then taken off supervision and you sit with your peers to eat your meals away from staff supervision so it then becomes your control, your choice as to whether or not you complete your meal. Things like you have to fill your glasses of juice to the top of the glass but as soon as you are not supervised it is then in your head you do not have to fill your glasses. All these silly little things and you have got to eat all the sauce of your meals so if you have a gravy sauce it has to be eaten along with the meal and a lot of people try to avoid the sauce because that is where a lot of the fat lies. So again it becomes when you come off the supervision table it is then your choice as to whether you clean your plate. There is a lot of peer supervision and peer support goes on at the	<i>becomes up to you</i> <i>You decide</i> <b>Sense of greater choice/control</b>  <u>Activity becomes self-controlled</u>     <u>scary</u>  <u>self-doubt at ability to manage normalised level of control</u>  <u>learning to trust self</u>  <u>not relying on eating disorder</u>  <u>greater control of meals in treatment/reduction of level of supervision</u>  <b>coping with/managing anorectic thoughts</b>
Reduction of restrictions and supervision		
Process of regaining greater control		Repeated use of phrases <i>it is your choice</i> <i>more choice</i>

<p>Empowering process</p> <p>Change in control back to self</p>	<p>table but at the end of the day it is your choice. So you get more choice with meal prep because you are choosing your own meals, more choice coming off the supervision table and having to eat for yourself, more choice in terms of activity when you get your walks. Where else... when you get to have your time out gets increased and you start to get meal passes so you will actually go out with family and friends and have a meal out whether it be a lunch or dinner so maybe you are going into a restaurant and you are having to order food yourself and you are not supervised. It is with family and friends and you get two hours out to do that or three hours and you get snack passes as well to go out with family and friends to go out and have a snack. You then move up to having a day pass so you have a full day out from breakfast to maybe supper. So lunch and dinner may be at home when you are preparing it yourself or your family is preparing it and then you go on to having your overnight passes so you are actually getting to go home and stay home so that involves having a supper out and a breakfast out and you have the control of how you manage your activity levels when you are at home and how you eat when you are at home. So there is more trust, more control.</p> <p><b>I:</b> how do you feel about that whole process?</p> <p><b>P:</b> again it is scary to start with because you think can I cope, can I manage but then as you actually do manage and cope without using eating disorder behaviours it is so empowering and you think I can actually do this, I can take control, I can take a normalised control over my well-being and it is me in charge here, it is not the eating disorder, it is my choice. I am choosing to eat and no one is telling me to do this, it is my choice.</p>	<p><u>Greater opportunities for meal passes to eat out unsupervised</u></p> <p><u>Moving from meal to day pass</u></p> <p><b>Sense of gaining greater freedom/less restricted</b></p> <p><u>Regaining control</u></p> <p><u>More self- trust and control</u></p> <p><u>Scary</u> <u>Self-doubt of ability to cope</u> <u>Process empowering</u> <u>Regaining normalised control over self</u> <u>Regaining control from eating disorder</u></p> <p><b>Sense of greater choice</b> <i>My choice</i></p>
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**APPENDIX 8**

**Table of themes generated for Participant 3**

Table of super-ordinate and sub-ordinate themes for Participant 3

Super-ordinate and sub-ordinate themes	Key words from transcript
<b><i>Shifts in control</i></b> <ol style="list-style-type: none"> <li>1. Loss and handing over of control</li> <li>2. Coping with restrictions</li> <li>3. Removal of choice as necessary</li> <li>4. Process of regaining control</li> </ol>	<ol style="list-style-type: none"> <li>1. “No control over food”/ “lost all control”/ “I had to hand over all that control”</li> <li>2. “Horrendous”/ “Having all the restrictions put on me was hard”</li> <li>3. “Process is essential”/ “have to have your behaviours curtailed”/ “It has to have that tightness”</li> <li>4. I have gained choice/normalised level of control/more in control/get more choice</li> </ol>
<b><i>Experience of transition</i></b> <ol style="list-style-type: none"> <li>1. Loss of normality</li> <li>2. Desire for practical skills</li> <li>3. Fear of discharge</li> </ol>	<ol style="list-style-type: none"> <li>1. “Having to remove myself from parents and friends”</li> <li>2. “Going out into social areas eating/ “activities to do with living”</li> <li>3. “I’m terrified”/ “huge cloud hangs over my head”/ “so scared”</li> </ol>
<b><i>Perceptions of staff approach</i></b> <ol style="list-style-type: none"> <li>1. Difficulties accessing staff</li> <li>2. Value of staff support</li> <li>3. Importance of holistic approach</li> </ol>	<ol style="list-style-type: none"> <li>1. “Staffing levels were low”/ “lot of time free without therapy”</li> <li>2. “So understanding and patient”/ “compassion”</li> <li>3. “Programme more holistic”/ “consideration of underlying issues”</li> </ol>
<b><i>Sharing with peers</i></b> <ol style="list-style-type: none"> <li>1. Peer support</li> <li>2. Learning from peers</li> <li>3. Comparison and envy of peers</li> <li>4. Coping with peers’ distress</li> </ol>	<ol style="list-style-type: none"> <li>1. “Lot of peer support”/ “feel not you are not alone with illness”</li> <li>2. “Exchange experiences”/ “learn from people”/ “new behaviours”/ “new tricks of trade”</li> <li>3. “comparing myself to peers”/ “envious of them”/ “need to be emaciated”</li> <li>4. “so upsetting”, “having to experience others distress is hard”</li> </ol>
<b><i>Struggle of recovery</i></b> <ol style="list-style-type: none"> <li>1. Role of self-motivation</li> <li>2. Recovery as slow process</li> <li>3. Emotional struggle</li> <li>4. Coping with symptoms</li> </ol>	<ol style="list-style-type: none"> <li>1. “Made deal with myself”/ “to be all or nothing”/ “Commit 100%”</li> <li>2. “Long, slow process”</li> <li>3. “A lot of tears, lot of frustration, lot of distraction”</li> <li>4. “Drive still remains”/ “thoughts are still there”</li> </ol>
<b><i>Process of self-discovery in recovery</i></b> <ol style="list-style-type: none"> <li>1. Rediscovering self-identity</li> <li>2. Separating self from AN</li> </ol>	<ol style="list-style-type: none"> <li>1. “Having to find my own identity”/ “Understanding who I am”</li> <li>2. “Had become so absorbed with the eating disorder”/ “Process of separation”</li> </ol>

**APPENDIX 9**

**Summary tables of themes generated for each participant**

### Clustering and distribution of recurrent super-ordinate themes (themes present in 1/3 or more of sample)

Clustering of recurrent super-ordinate themes into Master Themes	Recurrent super-ordinate themes (present in 1/3 or more of sample)	Distribution of recurrent super-ordinate themes for each participant																					
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	Total
Shifts in control	Shifts in control	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓		✓	✓	✓	✓			✓	17/21
	Admission/initial experiences of treatment	✓	✓				✓			✓	✓				✓					✓			7/21
Experience of transition	Loss of normality in treatment	✓	✓	✓	✓	✓		✓				✓			✓			✓	✓				13/21
	Adjustment/treatment as a safe place				✓	✓		✓	✓	✓	✓			✓	✓	✓	✓	✓	✓		✓		14/21
	Perceptions of discharge and changes in support	✓	✓	✓	✓		✓	✓	✓		✓			✓	✓			✓		✓			13/21
Importance of supportive staff relationships	Perceptions of staff approach & support	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	20/21
	Being seen as an individual	✓	✓	✓	✓	✓		✓			✓	✓	✓	✓		✓		✓	✓	✓			14/21
Sharing with peers	Sharing with Peers	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	20/21
Process of recovery & self discovery	Struggle of recovery	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓		✓	✓	✓	✓	✓	19/21
	Self-motivation in recovery	✓		✓	✓	✓					✓	✓						✓					7/21
	Rediscovering the self in recovery	✓	✓	✓		✓		✓	✓			✓	✓	✓		✓	✓	✓	✓			✓	15/21



**Distribution of master themes and sub-ordinate themes across sample**

Master Themes	Sub-ordinate themes	Distribution of master themes and sub-ordinate themes for each participant																				
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Shifts in control				✓		✓	✓		✓		✓	✓				✓	✓	✓				
	Handing over control of eating behaviours											✓										
	Living within the restrictive environment	✓	✓	✓	✓	✓		✓			✓						✓					✓
	Regaining control		✓	✓	✓	✓	✓				✓					✓						
	Seeking greater collaboration		✓		✓			✓				✓				✓			✓			
Experience of transition	At the start I didn't want to be here	✓	✓				✓			✓	✓					✓				✓		
	Treatment as a safe environment				✓	✓	✓	✓		✓	✓			✓		✓	✓	✓			✓	✓
	Loss of normality	✓	✓		✓	✓	✓		✓			✓				✓		✓				
	Back to reality: concerns about loss of support and fear of relapse	✓	✓	✓	✓		✓		✓		✓		✓		✓			✓	✓			
Importance of supportive staff relationships	Importance of trust and making connections		✓				✓						✓	✓		✓		✓				
	Importance of being seen as a whole person not a walking eating disorder	✓	✓	✓	✓		✓	✓			✓	✓	✓			✓		✓	✓	✓		
	Perceived inconsistencies in staff support	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓

### Distribution of master themes and sub-ordinate themes across sample

Master Themes	Sub-ordinate themes	Distribution of master themes and sub-ordinate themes for each participant																				
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Sharing with peers	I am not alone – benefits of peer support	✓		✓		✓		✓		✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Learning from peers	✓	✓	✓		✓				✓	✓		✓			✓		✓				
	Envy of emaciated peers	✓		✓			✓	✓				✓		✓						✓		
	Coping with others’ distress			✓							✓					✓		✓	✓			
Process of recovery and self-discovery	Recovery as an arduous process	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓		✓	✓	✓	✓	✓
	Role of self-motivation	✓		✓	✓						✓	✓						✓				
	Self-discovery and regaining confidence	✓	✓	✓		✓	✓	✓			✓	✓	✓	✓		✓	✓	✓	✓			✓

**APPENDIX 10**

**Sample of extracts for master theme: sharing with peers**

**Sample of extracts for master theme: sharing with peers<sup>2</sup>**

**4.2.4.1 I am not alone: the benefits of peers support**

*“It is a relief to know, we do not all think exactly the same but there is someone there who does kind of understand because you feel sometimes you are talking to your therapist and that they do not seem to get it.” (Participant 1)*

***“Being around peers is positive in the sense that you get a lot of peer support and you are with people who are experiencing the same thing as you, it makes you feel you are not alone with the illness...”(Participant 3)***

*“...when I was at home nobody understood and when I said things people would look at me but when you see things in there people completely understand what you mean. It is quite a relief to hear people saying I know what you mean because before nobody understood.” (Participant 5)*

*“When you are out in the real world people are quite judgemental...Whereas here everybody knows exactly what everyone has got...you do not notice the way people are so it means you can be a bit more relaxed and you do not feel ashamed of yourself.” (Participant 11)*

***“...It is really hard because there are a few people who are really horrible and life and you can tell a lie about their eating habits and lie about stupid things. It is like being in the Big Brother house it is a bad atmosphere to be in.” (Participant 14)***

**4.2.4.2 Learning from peers**

***“...you can learn a lot of new behaviours and a lot of new tricks to the trade! But is really good in terms of being able to hear how other people have gotten over, how they have gotten over the drive to exercise and how they have managed to eat certain foods. How did they cope with it and what did they do?” (Participant 3)***

*“You get advice from other people and you can see other people’s point of view and reflect in their experiences...”( Participant 15)*

*“Sometimes it can stick in your head and you start using it or whatever. The farther you get in treatment you realise that it is rubbish and shake your head. You remember you were like that once too.” (Participant 6)*

*“...sometimes being with people who are really bad with the behaviours can have a negative impact on food as well because you can start picking them up and it can become quite stressful.” (Participant 11)*

*“...They (peers) can insert behaviours that are quite negative and it is easy to pick up on other people’s behaviours.” (Participant 13)*

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<sup>2</sup> Extracts highlighted in bold are also presented in the Results chapter

#### **4.2.4.3 Envy of emaciated peers**

*“I always find myself looking at other patients and comparing myself to them...I just think they are thin and what do they think of me.” (Participant 1)*

***“You are always comparing yourself ...it is hard when are eating meals and people are not finishing them. You feel greedy. You have got to remember you were like that to start with and they are going to end up in the same place you are.” (Participant 7)***

*“...when new admissions come in and they are really struggling that can make it harder for you. You watch them not finishing their meal and you think I have got to finish this and they are not finishing theirs.” (Participant 8)*

*“It is quite nice when you first come in you are not the only one but you do think you do not deserve to be here. You think I look so much bigger than these people and I do not deserve to take this bed.” (Participant 12)*

*“...if someone new comes in, I freak out and look at the size of me, what are they going to think of me, there are going to be thinking that of me and I worry about that.” (Participant 14)*

#### **4.2.4.4 Coping with others' distress**

***“...we are encouraged to support each other but not so much that it affects ourselves but sometimes it feels as if we are the only ones offering support and are taking that burden onto yourself so it means it doesn't help ourselves as we get quite stressed.” (Participant 11)***

*“I do not like dealing with other people's problems...for two months I was focussed on helping other people's treatment and their fears were coming into myself and I wasn't thinking about myself as much.” (Participant 15)*

*“...being in an environment where it's fair to say everyone has their own problems but you say why should their problems be enforced on mine, should that be something to deal with, is it necessary? It is a lot harder and is made a lot harder than it should be because of that.” (Participant 15)*

*“...people are at different stages in treatment it is quite hard, the majority of people are here obviously because they want to get well and fight it but sometimes...you get people who don't and it is hard to be around those people when you're trying to stay positive and determined...” (Participant 17)*

**APPENDIX 11**

**Participant summary letter**

## Experiences of specialist inpatient treatment for anorexia nervosa

Tayside Eating Disorders Service  
4 Dudhope Terrace  
Dundee  
DD3 6HG  
Tel: 01382 306160  
Fax:  
www.nhstayside.scot.nhs.uk

Date  
Our Ref      VS

Enquiries to      Vivien Smith  
Email

Dear (insert name)

In (insert month and year) you participated in a research interview at \*\*\*\*\*. You were asked about your experiences of your eating difficulties and your current inpatient treatment. As discussed during the interview, I am writing to you to thank you again for your time and to give a summary of our research findings.

### ***What was the purpose of the study and who took part?***

The aim of the study was to help us understand the experiences of people within inpatient settings who have eating difficulties. Twenty-one adult females with a diagnosis of Anorexia Nervosa who were undergoing inpatient treatment at the \*\*\*\*\* took part in the study. The interviews were carried out between January 2009-January 2010. The results of the study were also reviewed by a small group of individuals who were currently receiving inpatient treatment at \*\*\*\*\*. This helped to check our understanding of what had been discussed in the interviews. **All personal information was removed to protect the anonymity of participants.**

### ***What were the main findings of the study?***

Overall, most participants were happy with the treatment they received at \*\*\*\*\* and contrasted it with unsatisfactory treatment they had received elsewhere before. Participants experienced the programme as challenging especially in the beginning. However, they believed that the firm structure was highly beneficial and necessary for recovery. It allowed them to gain insight into themselves and their difficulties, helping their recovery.

Analyses of the research interviews revealed 5 main themes:

<b>Themes</b>	<b>Sub-themes</b>	<b>Description</b>
<i>1. Shifts in control</i>	1.1 Handing over of control of eating behaviours 1.2 Living within the restrictive environment 1.3 Regaining control 1.4 Seeking greater collaboration in treatment	Participants felt they were handing over control of their eating behaviours at the start of treatment. They disliked the treatment restrictions but felt they were essential. Participants felt they were regaining personal control over time and wanted to be more involved.
<i>2. Experience of transition</i>	2.1 At the start I didn't want to be here 2.2 Treatment as a safe environment 2.3 Loss of normality: inside the safety bubble 2.4 Back to reality: concerns about loss of support and fear of relapse	Participants described feeling upset at the start but later viewed treatment as a safe place. They felt a loss of normality and wanted to practice skills in outside settings. They described feeling worried about discharge.
<i>3. The importance of supportive staff relationships</i>	3.1 Importance of trust and making connections 3.2 Importance of being seen as a whole person not a walking eating disorder 3.3 Perceived inconsistencies in staff support	Participants felt it was important to have a trusting relationship with staff and to be seen as an individual. Participants valued treatment, which addressed their physical and emotional needs. However, some participants highlighted a need for greater staff availability and consistency.
<i>4. Sharing with peers</i>	4.1 I am not alone – benefits of peer support 4.2 Learning from peers 4.3 Envy of emaciated peers 4.4 Coping with others' distress	Participants felt understood and supported by their peers. However, some participants felt upset when comparing themselves to their peers and became aware of other eating disorder behaviours.
<i>5. Process of recovery and self discovery</i>	5.1 Recovery as an arduous process: differences between physical recovery and full recovery 5.2 Role of self-motivation 5.3 Self-discovery and regaining confidence	Participants described the recovery process as an ongoing difficult process. Self-motivation was seen as important to accept treatment. Some participants felt that they were able to develop a greater self-esteem and self-identity in treatment.



***How did participants feel about taking part in the study?***

All participants felt their involvement in the research was a positive experience and allowed them to reflect on their treatment experiences.

***What contribution do these findings make?***

These findings represent a significant contribution to our understanding of the views and experiences of individuals undergoing inpatient treatment for Anorexia Nervosa. We hope that the findings of the study will contribute to future improvements in the inpatient treatment for people with eating difficulties.

***What will happen to the findings of this study?***

The results of the study will be submitted as a thesis to Edinburgh University for review as part fulfilment of Doctorate in Clinical Psychology degree at the University of Edinburgh. We hope to later publish this study in reports, scientific journals and present the results at conferences.

**In the study, your name was replaced with a participant number, so that it will not be possible for you to be identified in any reporting of the data gathered. Direct quotes from interviews were anonymised and any information that might identify has been removed.**

***How to contact us about the results of this study?***

If you would like to provide any feedback on the results of this study or would like further information, please contact myself using the contact details below.

Name of Lead Researcher:	Vivien Smith
	Trainee Clinical Psychologist
Address	NHS Tayside Eating Disorders Service
	4 Dudhope Terrace
	Dundee, DD3 6HG
Telephone:	01382 306160
Email:	viviensmith@nhs.net

Thank you again for taking part in the study.

Yours sincerely

**Vivien Smith**  
**Trainee Clinical Psychologist**

**APPENDIX 12**

**Journal scope and author guidelines: *European Eating Disorders Review***

**(Selected journal for systematic review and journal article)**

## **European Eating Disorders Review**

### **Aims and Scope**

*European Eating Disorders Review* publishes authoritative and accessible articles, from all over the world, which review or report original research that has implications for the treatment and care of people with eating disorders, and articles which report innovations and experience in the clinical management of eating disorders. The journal focuses on implications for best practice in diagnosis and treatment, (rather than on research methodology). The journal also provides a forum for discussion of the causes and prevention of eating disorders, and related health policy.

The aims of the journal are to offer a channel of communication between researchers, practitioners, administrators and policymakers who need to report and understand developments in the field of eating disorders.

The journal reports on useful research and experience related to the treatment and prevention of eating disorders in primary care and hospital settings, with special attention to therapy oriented translational research, high quality reviews, clinical trials and pilot innovative therapy approaches. It provides information about 'good practice' and systematic reviews. It offers a forum for new thinking about the nature, incidence, diagnosis and clinical management of eating disorders (namely anorexia nervosa, bulimia nervosa, ED not otherwise specified, binge eating disorders, and other abnormal eating or feeding behaviors associated with obesity). It provides information about events, training, policy and publications relating to eating disorders.

Type of manuscripts:

Original Reports, including empirical Research Reports and Theoretical Systematic Reviews; Brief-Reports (Preliminary findings of treatment trials and programmes; standardization and validation of psychometric measures, Development of new instruments and measures, original empirical research that can be succinctly summarised and does not require extensive elaboration). Case reports (single or series of cases, following innovative therapies or designs); Themed collections of peer-reviewed papers in special sections or Issues;

Researchers, practitioners and trainees in clinical and health psychology, psychiatry, nursing, medicine (including General Practice), endocrinology, nutrition, psychotherapy and counselling are invited to contribute and to read the journal regularly, by personal subscription or in their institution library.

## Author Guidelines

### Manuscript Submission

European Eating Disorders Review has now adopted ScholarOne Manuscripts, for online manuscript submission and peer review.

**Illustrations** must be submitted in electronic format. Save each figure as a separate file, in **TIFF** or **EPS** format preferably, and include the source file. We favour dedicated illustration packages over tools such as Excel or Powerpoint. Grey shading (tints) are not acceptable. Lettering must be of a reasonable size that would still be clearly legible upon reduction, and consistent within each figure and set of figures. Supply artwork at the intended size for printing. The artwork must be sized to the text width of 7 cm (single column) or 15 cm (double column).

**Manuscript style.** The language of the journal is English. All submissions including book reviews, must have a title, be printed on one side of the paper, be double-line spaced and have a margin of 3cm all round. Illustrations and tables must be printed on separate sheets, and not be incorporated into the text.

- The **title page** must list the full title, short title of up to 70 characters and names and affiliations of all authors. Give the full address, including e-mail, telephone and fax, of the author who is to check the proofs.
- Include the name(s) of any **sponsor(s)** of the research contained in the paper, along with **grant number(s)**.
- Supply an **abstract** of up to 150 words for all articles [except book reviews]. An abstract is a concise summary of the whole paper, not just the conclusions, and is understandable without reference to the rest of the paper. It should contain no citation to other published work.
- Include up to five **keywords** that describe your paper for indexing purposes.

**Reference style.** The APA system of citing sources indicates the author's last name and the date, in parentheses, within the text of the paper.

**A. A typical citation of an entire work consists of the author's name and the year of publication.**

Example: Charlotte and Emily Bronte were polar opposites, not only in their personalities but in their sources of inspiration for writing (Taylor, 1990). Use the last name only in both first and subsequent citations, except when there is more than one author with the same last name. In that case, use the last name and the first initial.

**B. If the author is named in the text, only the year is cited.**

Example: According to Irene Taylor (1990), the personalities of Charlotte. . .

**C. If both the name of the author and the date are used in the text, parenthetical reference is not necessary .**

Example: In a 1989 article, Gould explains Darwin's most successful. . .

**D. Specific citations of pages or chapters follow the year .**

Example: Emily Bronte "expressed increasing hostility for the world of human relationships, whether sexual or social" (Taylor, 1988, p. 11).

**E. When the reference is to a work by two authors, cite both names each time the reference appears .**

Example: Sexual-selection theory often has been used to explore patters of various insect matings (Alcock & Thornhill, 1983) . . . Alcock and Thornhill (1983) also demonstrate. . .

**F. When the reference is to a work by three to five authors, cite all the authors the first time the reference appears. In a subsequent reference, use the first author's last name followed by *et al* . (meaning "and others") .**

Example: Patterns of byzantine intrigue have long plagued the internal politics of community college administration in Texas (Douglas *et al* ., 1997) When the reference is to a work by six or more authors, use only the first author's name followed by *et al* . in the first and all subsequent references. The only exceptions to this rule are when some confusion might result because of similar names or the same author being cited. In that case, cite enough authors so that the distinction is clear.

**G. When the reference is to a work by a corporate author, use the name of the organization as the author .**

Example: Retired officers retain access to all of the university's educational and recreational facilities (Columbia University, 1987, p. 54).

**H. Personal letters, telephone calls, and other material that cannot be retrieved are not listed in References but are cited in the text .**

Example: Jesse Moore (telephone conversation, April 17, 1989) confirmed that the ideas. . .

**I. Parenthetical references may mention more than one work, particularly when ideas have been summarized after drawing from several sources. Multiple citations should be arranged as follows .**

Examples:

- List two or more works by the same author in order of the date of publication: (Gould, 1987, 1989)
- Differentiate works by the same author and with the same publication date by adding an identifying letter to each date: (Bloom, 1987a, 1987b)
- List works by different authors in alphabetical order by last name, and use semicolons to separate the references: (Gould, 1989; Smith, 1983; Tutwiler, 1989).

All references must be complete and accurate. Where possible the DOI for the reference should be included at the end of the reference. Online citations should include date of access. If necessary, cite unpublished or personal work in the text but do not include it in the reference list. References should be listed in the following style:

### **Journal Article**

Gardikiotis, A., Martin, R., & Hewstone, M. (2004). The representation of majorities and minorities in the British press: A content analytic approach. *European Journal of Social Psychology*, 34, 637-646. DOI: 10.1002/ejsp.221

### **Book**

Paloutzian, R. F. (1996). *Invitation to the psychology of religion* (2nd ed.). Boston: Allyn and Bacon.

### **Book with More than One Author**

Natarajan, R., & Chaturvedi, R. (1983). *Geology of the Indian Ocean*. Hartford, CT: University of Hartford Press.  
Hesen, J., Carpenter, K., Moriber, H., & Milsop, A. (1983). *Computers in the business world*. Hartford, CT: Capital Press. and so on.  
The abbreviation *et al.* is not used in the reference list, regardless of the number of authors, although it can be used in the text citation of material with three to five authors (after the initial citation, when all are listed) and in all parenthetical citations of material with six or more authors.

### **Web Document on University Program or Department Web Site**

Degelman, D., & Harris, M. L. (2000). *APA style essentials*. Retrieved May 18, 2000, from Vanguard University, Department of Psychology Website: [http://www.vanguard.edu/faculty/ddegelman/index.cfm?doc\\_id=796](http://www.vanguard.edu/faculty/ddegelman/index.cfm?doc_id=796)

### **Stand-alone Web Document (no date)**

Nielsen, M. E. (n.d.). *Notable people in psychology of religion*. Retrieved August 3, 2001, from <http://www.psywww.com/psyrelig/psyrelpr.htm>

**Journal Article from Database**

Hien, D., & Honeyman, T. (2000). A closer look at the drug abuse-maternal aggression link. *Journal of Interpersonal Violence*, 15 , 503-522. Retrieved May 20, 2000, from ProQuest database.

**Abstract from Secondary Database**

Garrity, K., & Degelman, D. (1990). Effect of server introduction on restaurant tipping. *Journal of Applied Social Psychology*, 20 , 168-172. Abstract retrieved July 23, 2001, from PsycINFO database.

**Article or Chapter in an Edited Book**

Shea, J. D. (1992). Religion and sexual adjustment. In J. F. Schumaker (Ed.), *Religion and mental health* (pp. 70-84). New York: Oxford University Press.